COMMUNICATING HEALTH:

Priorities and Strategies for Progress

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Priorities and Strategies for Progress

Action Plans To Achieve the Health Communication Objectives in *Healthy People 2010*

July 2003

Office of Disease Prevention and Health Promotion

HEALTHY PEOPLE 2010

U.S. Department of Health and Human Services
Office of Disease Prevention and Health Promotion

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BACKGROUND ON THE HEALTH COMMUNICATION FOCUS AREA IN HEALTHY PEOPLE 2010

Healthy People 2010 is about improving the health of each individual, the health of communities, and the health of the Nation. It is based on a systematic approach to health improvement. *Healthy People 2010* has two overarching goals: increase the quality and years of healthy life, and eliminate health disparities. These goals have been elaborated in 467 objectives in 28 focus areas. Collectively, they provide a thorough picture of the Nation's health at the beginning of the decade, set forth national goals and targets to be achieved by 2010, and provide a framework to monitor progress over time.

Healthy People is a collaborative effort managed by the Office of Disease Prevention and Health Promotion (ODPHP) of the U.S. Department of Health and Human Services (HHS). *Healthy People 2010* represents the third time HHS has developed 10-year health objectives for the Nation. The Healthy People initiative began in 1979 with *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* and was followed in 1980 with *Promoting Health/Preventing Disease: Objectives for the Nation*, and in 1990 by *Healthy People 2000.*

Each focus area in *Healthy People 2010* has a designated lead agency. ODPHP is the lead agency for the Health Communication Focus Area. The main responsibilities of the lead agency are to coordinate activities related to the measurement and implementation of the objectives in its focus area and generally to promote awareness of and action on the issues represented by the objectives. As the focus area lead agency, ODPHP typically convenes meetings, coordinates activities, and encourages collaboration among organizations and individuals working on issues and projects related to the health communication objectives. ODPHP convenes the Health Communication Focus Area Work Group as needed to provide assistance with focus area activities. ODPHP also coordinates and prepares progress reviews for the Health Communication Focus

Area throughout the decade, including the mid-course review scheduled for 2005. A Health Communication Focus Area progress review was held June 24, 2003. ODPHP works with other HHS agencies and offices, State and local government agencies, universities, nonprofit organizations, healthcare providers, public health professionals, professional and trade associations, individual researchers, health education professionals, and any other individuals or organizations committed to making progress on the health communication objectives.

The objectives were not intended to be the responsibility of the government alone, nor indeed can they be achieved solely through Federal efforts. Because of the nature of the issues raised by the objectives, many stakeholders share responsibility for taking action to achieve progress. The Federal Government and HHS in particular may have indirect or little influence on some of the factors underlying the objectives. Partnerships and collaboration across many sectors will be key to the achievement of the objectives by the end of the decade.

INTRODUCTION TO THE HEALTH COMMUNICATION ACTION PLANS

Communication is increasingly recognized as a necessary element of all efforts to improve health. Health communication is the study and use of communication strategies to inform and influence individual and community decisions that enhance health (U.S. Department of Health and Human Services, 2000, p. 11-3). The inclusion of the Health Communication Focus Area for the first time in *Healthy People 2010* confirms the importance of communication as an intellectual framework, a scientific endeavor, and a set of processes and interventions for health improvement. Communicating about health is also an everyday part of life. Mass media coverage, entertainment programming, and public policy debates are important places for public communication about health.

Health communication can contribute to all aspects of disease prevention and control, health promotion, and medical and dental care. It is relevant in a number of contexts of our lives as individuals, patients, members of families and communities, workers, civic participants, and voters. Thus, health communication is critical for people's exposure to, search for, and use of health information; individuals' ability to reduce or eliminate unhealthy behaviors and adopt healthy behaviors; and individuals' and community groups' ability to make decisions about the health of their workplace, their community, and our society. Furthermore, health communication is central to people's ability to gain access to the public health and healthcare systems; health professional-patient interactions; people's ability to engage in appropriate self-care and chronic disease management; and people's understanding of clinical recommendations and expected outcomes. Communication is critical to the work of health professionals and their interactions with each other, their patients, and the information they create and use. Health communication principles must inform the dissemination of information about individual and population health risks, the construction of public health messages and campaigns, the images of illness and health in the mass media and the larger culture, and the development of e-health applications, including online personal health records, health Web sites, interactive personal health tools, and telemedicine systems.

Health communication research, teaching, training, and practice cross many disciplines and academic boundaries. Health communication is an established category of research and teaching within the discipline of communication. Health communication is also a part of many elements of public health, medical, dental, and pharmacy training and practice, particularly in the areas of public information campaigns, community and patient education, and provider-patient communication. Some of these same aspects of health communication are also part of the field of medical sociology. The study and application of communication and information technologies to health and health care is a part of communication research and medical informatics, an area of research in academic medical centers, healthcare organizations, technology companies, and the government.

The six objectives in the Health Communication Focus Area represent this diversity of topics and variety of theoretical and methodological approaches. The objectives are designed to stimulate actions that result in progress in each area by the year 2010. The six objectives address the diffusion of the Internet to households, the quality of health Web sites, health literacy, provider-patient communication, research and evaluation of communication programs, and Centers of Excellence in health communication. Even though each of the objectives can be considered independently, there is considerable overlap among them. For example, making sure that patients and providers can adequately share useful information with each other is critical to improve both health literacy and provider-patient communication. Another example is the pair of objectives on the use of the Internet for health improvement. One objective focuses on increasing access to the Internet in households and the other on improving the quality of health Web sites. Both are necessary to ensure that the Internet becomes an equitably distributed resource to deliver health information and services that users can trust.

The eclectic and innovative nature of the objectives presents two challenges: (1) how to measure multifaceted phenomena to establish baselines, targets, and progress and (2) how to identify appropriate actions that will produce change and movement toward the targets. When the chapter was published in *Healthy People 2010* in January 2000, five of the six objectives were labeled "developmental." This designation means that there were no recognized national data sources to measure five objectives. Since then, two new data sources are being created, and one data source has been identified as part of an ongoing national survey. These sources are discussed in more detail in the relevant action plans. The process of creating and identifying data sources has had the additional benefit of generating lively discussion in the health communication field about the relevant concepts and dimensions for each objective and topic area. Although individual programs and interventions have had specific targets and outcome measures in the past, the idea of national objectives that encompass issue areas with many different types of programs, interventions, and activities is an innovation in the field.

The second challenge—identifying appropriate actions to achieve progress—is addressed by the six action plans in this publication. The action plans are a product of discussion and collaboration among individual drafters of background papers, small groups of subject experts, the Office of Disease Prevention and Health Promotion (ODPHP), which is the lead agency for the Health Communication Focus Area, and the health communication field at large. In the summer of 2001, ODPHP convened a Steering Committee to help plan a 1-day meeting to bring together small groups of subject experts for each objective. ODPHP then commissioned individuals to draft background papers for each objective. Steering Committee members, drafters, and small group members are listed at the end of this report. Each paper was reviewed by the Steering Committee and distributed to the relevant participants of the small groups. During the meeting on October 12, 2001, each small group spent the day in discussion and rewriting of its own paper and action plan. Each group was given the same set of section headings and decided for itself how much detail to put into each of the sections. For example, some groups identified lead organizations and responsibilities, and others did not. These revisions were reviewed by ODPHP, and the papers were rewritten in the form of expanded action plans. The plans were redistributed to the small group members, the Steering Committee, and members of the Health Communication Focus Area Work Group. The action plans also were presented at the 2001 American Public Health Association meeting, the 2001 National Communication Association meeting, and the 2002 Kentucky Conference on Health Communication. The names of the organizations and individuals who participated in the October 12 meeting and the drafting and review of the action plans are listed in the acknowledgments section at the end of this publication.

The purpose of the action plans is to focus the attention of researchers, teachers, practitioners, policymakers, and organizations on the general strategies and specific steps that they can take in support of the objectives. In general, the strategies and action steps aim to raise awareness, generate new information, stimulate funding and innovative policies, promote evaluation, and encourage development of programs and interventions that support progress toward the targets for each objective. The action plans are not intended to be definitive in their current form. They are works in progress and will be reviewed and updated as needed.

Each of the action plans follows the same format and leads the reader through an understanding of the issues underlying the objective and its importance, some of the main factors that will affect progress on the objective, key participants needed to work on the strategies and action steps, and the strategies and action steps themselves. The interests of the public and specific populations in the objectives, strategies, and action steps are broad, diverse, and relevant to each of the plans. Some plans identify lead organizations and responsibilities, others do not; all the plans need more attention to these two categories. Where lead organizations and responsibilities have not yet been identified, public- and private-sector groups working in each of the areas can identify them as relevant activities emerge. ODPHP will continue in its traditonal role of coordination of public and private efforts rather than implementation and funding of specific activities.

The action plans represent the best ideas to date about how to make investments—financial, intellectual, educational, political, and practical—in health communication count. They provide a foundation on which to bring together individuals and groups that have a stake in the achievement of shared objectives.

Reference

U.S. Department of Health and Human Services. *Healthy People 2010.* 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

OBJECTIVE 11-1
INTERNET ACCESS IN THE HOME

DRAFTERS

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TEXT OF OBJECTIVE

Increase the proportion of households with access to the Internet at home.

SCOPE

The objective is intended to represent an important aspect of Internet access but cannot encompass all issues raised by and related to the subject. The objective means to serve the specific purpose of providing data on progress for Internet connections in the home and the general purpose of stimulating discussion about a wide range of Internet access issues.

MEASUREMENT

2000 Baseline: 26 percent of households

2010 Target: 80 percent of households

The objective is measurable. It seeks to determine how many households have established an Internet connection. Data are collected as part of the *Computer and Internet Use Supplement to the Current Population Survey*, U.S. Census Bureau. The supplement is fielded every 2 to 3 years, subject to funding availability.

There is a new strategy emerging in terms of measurement that may affect the long-term tracking of the objective. The most recent U.S. Department of Commerce study, *A Nation Online: How Americans Are Expanding Their Use of the Internet*, focuses on individual rather than household access. The report cites several reasons for this subtle but important change. As stated in the report:

- Focusing on individuals permits the study of such factors as age, gender, education, and employment status in determining computer and Internet use.
- Internet access occurs frequently outside the home, at such locations as work, schools, and libraries.
- A small but growing number of Internet connections are increasingly occurring over personal mobile devices, such as wireless phones and personal digital assistants, in addition to traditional desktop computers.

The most recent data indicate that Americans' use of information technologies has grown in all locations—home, workplace, school, and community settings. As of September 2001, 60.2 million U.S. homes (or 56.5 percent) had a personal computer. Seven of every eight households with computers (88.1 percent) also subscribed to the Internet. As a result, more than half of U.S. households (53.9 million homes, or 50.5 percent) had Internet connections.

Table 1 shows the baseline data and updates for the objective with household as the unit of measure. The National Center for Health Statistics, U.S. Department of Health and Human Services, is working with the Department of Commerce to determine if data are or will be available for the categories in the reporting template currently labeled "data not collected" or "data are statistically unreliable."

Inclusion of the Internet items on the Current Population Survey, however, cannot be guaranteed because of funding and

TABLE 1. INTERNET ACCESS SEPTEMBER 2001 (2000 UPDATE) AUGUST 2002 (2001 UPDATE)

	1998 Baseline (Percent)	2000 Update (Percent)	2001 Update (Percent)
TOTAL	26	42	51
Race and ethnicity			
AI/AN	DSU	DSU	DSU
A/PI	36	57	68
Asian	DNC	DNC	DNC
NHOPI	DNC	DNC	DNC
Black	11	24	31
White	30	46	55
Hispanic	13	24	32
Not Hispanic	28	43	52
AI/AN	DSU	DSU	DSU
A/PI	36	57	68
Black	11	24	31
White	30	46	55
Gender			
Female	15	30	40
Male	20	36	45
Education level			
Less than high school	5	12	23
High school graduate	16	30	40
At least some college	31	48	58
Geographic location			
Urban	28	42	51
Rural	22	39	49

Legend:

AI/AN—American Indian/Alaska Native
A/PI—Asian/Pacific Islander
NHOPI—Native Hawaiian or Other Pacific Islander
DSU—Data Statistically Unreliable
DNC—Data Not Collected

Source: U.S. Department of Commerce. *Computer and Internet use supplement to the current population survey*, September 2001. Available online at www.bls.census.gov/cps/computer/computer.htm.

space constraints on the questionnaire. Action needs to be taken to ensure that the current items plus additional items remain part of the survey or become part of a comparable data collection instrument.

ISSUES PERTAINING TO MEASUREMENT

The objective assesses Internet connection rates. Although Internet service providers can now provide "dial-up" service (via a standard telephone line) to virtually every home in the United States, not all homes currently have telephone access; in some rural areas, the cost of dial-up Internet connectivity may be prohibitive. In addition, recipients need some sort of client-side device (e.g., computer, television, or personal digital assistant [PDA]) to make use of the Internet service, and, for some families, the cost of these devices may be prohibitive. Future data collection should be oriented toward the assessment of "meaningful access," which is more than an Internet connection. Meaningful access encompasses all the factors that make an Internet connection valuable, such as basic computer literacy, ongoing technical support, and Web content of interest. Information about meaningful access would provide a more complete picture of the circumstances surrounding Internet connection rates and the types of interventions that have the greatest impact.

In addition, one cannot presume that an Internet connection in a household means that everyone in the home has access to it. Parents who are computer owners may not allow their children to use the computer. Or parents who are loaned a computer for work may keep it for their own use only. New items to assess household access might include questions about

- Who owns the devices connected to the Internet and who pays the connection fees (e.g., head of household, local school district, or employer)
- The amount of time users spend on personal or business use of the Internet
- The type of Internet connection (e.g., dial-up, digital subscriber line [DSL], cable modem, new options as they emerge)

- Households' access to technical support and any subsidies to sustain Internet connections over time.

Public policy has played a part in shaping perceptions of what constitutes "access" and its assessment as the basis for policymaking. Past and current public policy is based on the assumption that whatever needs individuals have for the Internet can be satisfied with public (community) access or purchase of a household connection at whatever price the market will bear. With few exceptions, such as very underserved rural and inner-city urban areas, public policy has not focused on making Internet connections easier and more affordable for households. Internet connections in the home have been cast as a personal decision related to households' ability to pay monthly connection fees. Consequently, public policy has been oriented toward ensuring access to computers and the Internet in public places, such as schools, public libraries, hospitals, and community centers. Not surprisingly, the government has paid much less attention to funding interventions to promote household connections than to funding interventions to promote community-level access.

The situation may change with broadband technologies. Corporate interest in mass diffusion of broadband technologies to support the delivery of multimedia content may prompt new debate on the public policy mechanisms needed to increase and sustain Internet connection rates. Typically, the economics of the "last mile" and the perception that some types of household connections, such as cable television and the Internet, were discretionary and nonessential made unlikely a workable policy for wired connections in the home other than telephone service. Telephone service was the exception and has been protected by the presumption of "universal service"; that is, all who want to should be able to connect to the telephone network, and basic service fees should be subsidized if necessary. However, dial-up connections to the Internet, which currently are the overwhelming majority, are unlikely to be included in any policy efforts.

A related policy and programmatic matter concerns the lack of attention to household Internet connections as a matter of health policymaking and program planning. Healthcare and public health professionals have been virtually silent on the importance of household Internet connections for access to health information and services. As of 2002, 110 million U.S. Internet users had searched for health information online on average three times a month (HarrisInteractive 2002). The inclusion of Internet access as a *Healthy People 2010* objective is an important first step to draw attention to the issue. The next step is for health policymakers and program directors to make household connections to the Internet part of their models, programs, and activities and to support meaningful access for everyone, especially the most underserved populations. Without this level of attention across the health sector, progress on the objective is likely to be slow for those populations with the greatest health risks.

STATE OF KNOWLEDGE ABOUT ISSUES REPRESENTED BY THE OBJECTIVE

The primary set of knowledge about Internet access and connections to the home comes from public debate and research of a phenomenon commonly referred to as "the digital divide." "Digital inclusion" has been proposed as an alternative framing of the issues. The Benton Foundation, which sponsors a Web site devoted to digital divide issues (www.digitaldividenetwork.org/content/sections/index.cfm), defines the digital divide as the "gap between those who can effectively use new information and communication tools, such as the Internet, and those who cannot. While a consensus does not exist on the extent of the divide (and whether the divide is growing or narrowing), researchers are nearly unanimous in acknowledging that some sort of divide exists at this point in time." The main issue of digital divide debates has been the unequal distribution of technology and technical skills in a society. The digital divide is conceptualized as both a national and global phenomenon.

Although the healthcare sector lags behind other sectors in the adoption of digital technologies, the Internet and related technologies and applications are becoming an increasingly important part of the way health and health care are managed in the United States. The text accompanying Objective 11-1 suggests that many healthcare organizations and public service agencies already use the Internet as one of their main channels for information dissemination. Access to the Internet and subsequent technologies is likely to become essential to gain access to health information, contact healthcare organizations and health professionals, receive services at a distance, and participate in efforts to improve local and national health.

As noted above, Objective 11-1 could potentially provide a basis for public policy to promote sustainable household connections to the Internet. Community settings, which in the past afforded some segments of the population greater access to computer technologies and the Internet, perhaps were sufficient for some types of information retrieval activities; however, they may be inadequate for the types of 24/7, highly personal health management functions that are emerging. On-demand, private, and secure connections are important so individuals can access the full range of health information and services available to them online. Because of the sensitivity of much health information for and about individuals and because of the added value of a person being able to pick up where they left off, such access can best occur in the home or on personal devices.

Not enough is known about how to make home Internet connections a reality and to sustain them beyond the initial investment. Assessments of consumer knowledge about how to buy computers or other Internet devices and how to acquire Internet connections are scarce, and little information is available on what types of training and other essential support are necessary to maintain Internet connections from the home. Some programs, such as Computers for Youth in New York City, have made training and technical support a cornerstone of their operations; as a result, they have experienced success in helping families maintain Internet connections. We also know that important financial barriers exist to acquiring Internet services. These barriers extend beyond the purchase of Internet-enabled devices. Many Internet service providers insist that customers have credit cards to pay for the service or pay a steep premium on monthly service charges if customers do not have reliable credit.

Several studies provide insight about individuals' motivations and interest in Internet connections at home (Ipsos-Reid, 2001; Lenhart, 2003; U.S. Department of Commerce, 2002; 2000). The discussion below focuses on reasons people offer to explain why they don't have Internet connections in their homes or, don't use the Internet.

Don't Want Internet. Several studies have documented that large numbers of people who are not connected to the Internet believe they don't want to be connected. The latest Pew Internet and America Life report on the digital divide found that 52 percent of respondents not currently connected to the Internet said they don't want or need to go online (Lenhart, 2003). In the *Falling Through the Net* report by the U.S. Department of Commerce, not wanting Internet access is the most common reason why households with computers have never been connected. Nearly one-third of respondents (30.8 percent) cite this as the most common reason. This reason is more important for seniors age 55 and older than for younger respondents. Another survey done by Ipsos-Reid found that not wanting Internet access is an important reason people do not intend to use the Internet. Among Internet "nonintenders," 40 percent say they have "no need for it," and 25 percent report they are "not interested in it." These findings suggest that attitudes, lack of Internet experience, and perhaps age are important factors related to Internet connections.

Computer Equipment Issues. Each of the studies reported here identify similar percentages of households that no longer own any computers (17 to 21 percent). Findings from the *Falling Through the Net* survey suggest that some people rely on Internet access outside the home. "Can use elsewhere" is the primary reason given by 10 percent of households with computers that have never been online and by 13 percent of households that have discontinued Internet use. The most recent Department of Commerce data show that slightly fewer households had discontinued Internet use (11 percent) because of being able to access the Internet elsewhere (2002). Work or other locations outside the home, however, may be unreliable places of access. Among Internet dropouts in the Pew study, 5 percent cite a change in job as the reason they are no longer online (Lenhart, 2003). Parenthood is one factor that seems to encourage people to think about getting Internet access in the home. Among Pew study respondents, 56 percent of parents who aren't online report that they probably or definitely will go online, while only 34 percent of non-parents predict they will go online at some point (Lenhart, 2003).

Financial Barriers. Although not wanting an Internet connection is the most common reason for not using the Internet, cost is a more important factor for some. *A Nation Online* findings from the Department of Commerce show that 26.9 percent of households making $50,000 or less annually rank cost as the number one reason. Household heads under age 45, female-headed families, and those with less education identified cost as an important reason they do not have an Internet connection. Cost was also a primary concern for 12 percent of Internet "nonintenders" responding to the Ipsos-Reid survey. As noted above, a lack of credit is also a financial barrier to getting Internet service. Customers without credit may find it difficult to get even a low-cost loan to purchase equipment, and customers without credit cards may be charged a steep premium every month to purchase an Internet connection.

Knowledge and Skill Barriers. Technology literacy appears to be a factor in deciding whether or not to go online. A total of 16 percent of Internet nonintenders responding to the Ipsos-Reid survey say that the biggest reason for not using the Internet is that they "don't know how to use it." Almost 30 percent of Pew respondents who are non-users say that the Internet is too complicated and hard to understand (Lenhart, 2003). People with a high school education or less are most likely to feel that the Internet is hard to use.

Attitude Barriers. A number of different attitudinal factors appear important to understand Internet connection rates, as discussed below.

- *Not Interesting or Useful.* The primary attitude (up to 60 percent of Internet nonintenders) mitigating against going online is respondents' perception that the Internet is not interesting or useful enough to use.

- *Not Enough Time.* Two of the surveys show that respondents do not use the Internet because of time constraints. In the *Falling Through the Net* survey, 9 percent of those who have never used the Internet and 10 percent of discontinued users with computers report "not enough time" as the main reason for not going online. In the Ipsos-Reid survey, 8 percent of Internet nonintenders also report this as a factor in their decision not to have an Internet connection.

- *Dangers in Going Online.* Being concerned about children's access was related to discontinuing Internet use among 3 percent of respondents in the *A Nation Online* survey. Among households with children, 68.3 percent were more concerned about the kind of material children may be exposed to on the Internet than on television. This concern, however, did not translate into lower rates of Internet access in the home. Among those who thought the Internet was a source of concern, 51.8 percent had Internet in the home. Further, parents responding to the Pew study indicated that being parents encouraged them to think about getting Internet access in the home (Lenhart, 2003). *A Nation Online* found that there is more concern about confidentiality over the Internet than with the telephone. In the Pew study, more than 40 percent of Internet nonusers report that they are worried about online pornography, credit card theft and fraud (Lenhart, 2003).

STAKEHOLDERS

As referred to here, a stakeholder is considered to be any contributor to efforts implied by or related to this objective, although the stakeholders identified in the paper are principally the drivers of efforts to increase Internet access and connections, even if their efforts do not reference the objective. Many groups and organizations have examined the issues related to increasing Internet access and closing the digital divide. They have also funded programs and made recommendations about how to close the divide. These include the U.S. Department of Commerce, the U.S. Department of Housing and Urban Development, the Federal Communications Commission, the Leadership Conference on Civil Rights, the Benton Foundation, the National Governors Association, the Children's Partnership, the Web-based Educational Commission, and many States and local school districts, among others.

Given the broad use of "stakeholder," all the following groups are included for consideration:

- Consumers
- Content providers or publishers
- Education associations and coalitions
- Educators
- Families
- Federal, State, local, and tribal governments
- For-profit corporations
- Hardware or telecommunications providers
- Investors
- Journalists
- Nonprofit, business, or trade associations and coalitions
- Foundations
- Public or private-sector organizations that provide technology training
- Research organizations
- Schools and universities
- Small businesses
- Unions

In terms of e-health, other stakeholders would include patients, public health agencies and organizations, healthcare professionals, and organizations that provide all types of health services. The Appendix presents a beginning list of stakeholders who could be organized to work on the objective.

TABLE 2. EXAMPLES OF STAKEHOLDER ACTIVITIES

Activity	Organization	Mission
Computers for Families (www.sbcff.org)	Santa Barbara Partners in Education and Santa Barbara County Education Office	Santa Barbara Computers for Families is placing 4,000 computers into the homes of Santa Barbara County schoolchildren whose parents cannot afford to purchase computers. The program will also provide training resources to the students, teachers, parents, and administrators who will use them. Support comes from Santa Barbara area businesses, foundations, and individuals as well as grants from the U.S. Department of Education.
Computers for Homebound and Isolated Persons (www.korrnet.org/chips/model.html)	Knoxville-Oak Ridge Regional Network (KORRnet), Knoxville-Knox County Community Action Agency	This network, funded by the U.S. Department of Commerce's Technology Opportunities Program, provides computers to eligible persons in their homes to allow them to stay connected to families and other sources of support.
Computers for Youth (www.cfy.org)	Computers for Youth Foundation, Inc. (CFY)	CFY has developed and tested a comprehensive and community-centric program in New York City Project Patchwork. All recipients receive a home computer, training, technical support, tailored Web content, and e-mail accounts on a community-wide system.
Computers In the Hood	13 Scribes Inc.	This project provides low-cost financing for families to buy low-cost computers, with installation and training included.
Indiana Legislative Agenda (http://ideanet.doe.state.in.us/legwatch/2001/05.html)	Indiana Department of Education Legislative Agenda	The Indiana Legislative Agenda supports the Realizing Equitable Access to Computers in Homes (REACH) program at $7.5 million per year. This program would have enabled thousands of low-income ninth-graders to have Internet access at home through their schools as well as additional learning capabilities. Funding was not supported for FY 2002 but will be sought again.

Continued

TABLE 2. EXAMPLES OF STAKEHOLDER ACTIVITIES, *Continued*

Activity	Organization	Mission
One Economy Corporation (www.one-economy.com)	One Economy Corporation	One Economy Corporation increases access to the Internet in low-income homes, aggregates the economic power of low-income households, helps low-income households accumulate assets in the form of social and economic capital, and fosters civic engagement.
Technology Goes Home (www.techboston.org/daley/mdbf.htm)	Boston Digital Bridge Foundation	This project prepares adults for employment opportunities and helps children improve academic performance by bringing technology to the homes of low-income families.

STATUS OF SELECTED STAKEHOLDER ACTIVITIES

Table 2 provides an overview of illustrative activities that organizations and groups are undertaking to bring technology and Internet connections to populations that would not otherwise have them. These activities range from policy and regulatory initiatives to specific financial assistance to acquire technologies and Internet connections.

Government. In the public sector, several organizations at the Federal, State, and local levels are interested in increasing home Internet access. They come from a range of agencies, including commerce, education, and health departments. Most government operations are becoming computerized, and government workers are increasingly dependent on computers. For example, *Healthy People 2010* contains another objective on Internet access for public health employees.

- Objective 23-1: Increase the proportion of Tribal, State, and local public health agencies that provide Internet and e-mail access for at least 75 percent of their employees and that teach employees to use the Internet and other electronic information systems to apply data and information to public health practice.

In addition, government is moving in the direction of

- Providing public access to government services through the Internet (e.g., bill payment, tax collection)
- Creating legislative agendas providing incentives to companies and end-users to access information and services online
- Creating legislative agendas to generate incentives for getting connected.

Although many of the initiatives that address digital inclusion have begun in schools and community centers, several groups have changed their focus to the home as the optimal Internet access point. The Web-based Education Commission (2000) examined home Internet access and came to the following conclusions:

> Home access is important for students doing research, taking online courses, and communicating with teachers and other learners. For parents, online access means new kinds of communication with their children's schools, with their children's teachers, and with other parents. For all households, Internet access is another way to connect with their communities and government services. Home access helps to advance economic opportunities: low-income users were the most likely to report using the Internet to look for jobs.

State governments have actively promoted the deployment of Internet technologies, particularly broadband technology, to resident businesses and the citizens of their States. State governments accomplish their vision of widespread deployment through a variety of means including loans, loan guarantees, State-match funding, subsidies, right-of-way initiatives, deregulation, and encouragement of a competitive telecommunications environment. Some State and local governments offer broadband as a service directly to their citizens.

For example, in California, the Riverside Computer Investment Program has helped 145 low-income households get computers, free training classes, free bilingual phone technical support, and Internet access. This public-private partnership's $20,000 capitalization provides a $225 subsidy per qualified low-income family to purchase their personal computer and keep monthly loan repayments below $20. In Texas, the Dallas County Workforce Board and the nonprofit Enterprise Foundation are supplying 1,000 low-income households in Dallas County with hardware, Internet access, and computer training through "Program @chieve" (NGA Center for Best Practices, 2001).

Despite recent events, including a downturn in the economy and the reordering of public policy priorities following September 11, 2001, States continue to promote broadband deployment. Michigan, for example, announced an initiative, "LinkMichigan," that will provide a statewide financing authority and a one-stop right-of-way authority to providers to assist with funding and to expedite deployment (http://medc.michigan.org/news/reports/economic/combo.asp?ContentId=94595AF5-BAE2-4BEE-856A-22DA8A130538).

As the primary regulatory body for telecommunications policy, the Federal Communications Commission (FCC) is an important stakeholder. Even though the FCC does not regulate the pricing of Internet access services directly, it has a broad policy interest and monitors developments related to Internet technologies and access. The FCC continues to examine barriers to more rapid diffusion of broadband services. The agency is also an entity that could extend the principle of "universal service" beyond telephony to encompass Internet access as a basic service for every household in the United States.

Business Community. Some employers have helped make home computer and Internet access available to their employees. In some cases they have provided access to low-cost systems and Internet service providers; in other cases they have provided the systems or Internet access. These employer initiatives have arisen for several reasons. Government incentives, such as tax breaks, have encouraged businesses to invest in their employees in new ways. Some employers may find it more cost-efficient to have an employee work at home rather than onsite where the business would have to furnish an office. With changes in work patterns, the shift to "information work," and increasing acceptance for telecommuting, employers have provided support for home-based workstations connected to the Internet. This delivers technology, access, and capability to the household and provides a very powerful model to develop a populace comfortable with information technologies in the home, not just at work. Other employers may see home Internet access as an employee benefit to boost morale and retention.

An important segment of the business community is vendors of technology, bandwidth, and improved applications. They are playing a key role in the deployment of access at the household level by providing hardware, software, Internet access, and technical assistance in ways that keep the issue on the public agenda and drive demand for new services and technologies. These vendors recognize the importance of these activities to their own business futures and are often willing to subsidize or provide seed money for demonstration projects. They also have played key roles on decisionmaking boards and task forces at every level of government and the public and private sector. Finally, to some extent their own research and development budgets contribute to the realization of the objective by continuing the process of technology development, which can contribute to enhanced accessibility and utility.

Other Intermediaries. Many other potential intermediaries can influence the achievement of Healthy People Objective 11.1. Nongovernment organizations, foundations, voluntary health associations, and healthcare systems have all played a role. As evidenced from the list of projects in the Appendix, many organizations are invested in closing the digital divide. Some are providing grant support to digital divide projects focused on the home, but these are minor in comparison to the school and community initiatives they fund. Other organizations do not provide funding but rather conduct research, raise public awareness, or lobby other agencies. Their work often keeps others apprised of the ever-shifting boundaries of the digital divide.

FACTORS THAT CAN INFLUENCE CHANGE

Given the current state of knowledge and the scope of current initiatives, a number of factors may be considered as principal facilitators of or barriers to change. Generational differences in familiarity and comfort with use of technology have been noted. As the population ages, household decisionmaking and resources will be shifted to those more likely to be comfortable with and interested in use of the Internet in the home. Improvements in technology and applications may make the Internet more user-friendly, attractive, and tailored to individual needs and wants, individual comfort, and perceived need, which could increase demand for access. Employers and school systems recognize the importance of home Internet access to improve the knowledge and skills of their employees and students. Table 3 summarizes these and other factors likely to influence change. At least three different frames of reference are necessary to understand the multiplicity of factors that will influence progress on Internet connection rates.

STRATEGIES AND SOLUTIONS

Looking at household penetration of communication and information technologies reveals at least three broad categories of decisionmakers in households: (1) those who have never used such technologies, (2) those who have tried and discontinued their use of such technologies, and (3) those who are currently using these technologies. These groups are not homogenous with respect to the motivations of individuals. For example, among those who have never tried these technologies at home, lack of awareness, fear of the unknown, and cost are relevant barriers, among others. At the same time, some barriers may be relevant at different times. For example, cost may be a barrier to initiating use, or it may be a reason someone decides to discontinue use. Each of these groups will need attention, and the strategies will need to be consistent with the reasons that individuals and households give for not having Internet connections at home.

The size and composition of the groups of household decisionmakers are likely to be influenced by a number of factors.

TABLE 3. FACTORS ABLE TO INFLUENCE CHANGE

Demand Side	Supply Side	Policy
■ Skills and training ■ Technology improvements ■ Public awareness and perception ■ Increased importance to employers and educators ■ Increased credit card, electricity, and phone access ■ Public awareness and public perceptions ■ Generational influences ■ Marketing campaigns ■ Concerns over privacy and safety ■ Trust ■ Economic conditions (e.g., slow down or recession) ■ Changing priorities (unforeseen historical events)	■ Technology improvements ■ Economic and market innovations ■ Lower costs of Internet connections and appliances ■ Improvements in telecommunications infrastructure ■ Predatory or fraudulent practices ■ Comprehensive technology services (now fragmented) ■ Consumer education ■ Availability of content that users want	■ Investment tax credits and loan guarantees ■ Subsidies ■ Regulation or deregulation ■ Public awareness and public perception ■ Encouragement of new suppliers of Internet access

The passage of time, perhaps a generation, will likely result in an increase in Internet penetration in the home, as the most reluctant users (aging baby boomers and senior citizens) are replaced by the now young, technology-savvy generations. Internet access has demonstrated rapid penetration compared with other major technologies such as telephones and color televisions. Whereas the telephone reached half of American homes after 71 years and color TVs took 18 years, according to the Electronic Industry Alliance, the Internet took only 10 years to reach 50 percent of homes in the United States.

The latest research from the Pew Internet and American Life project indicates that Internet access is not a static state (Lenhart, 2003). The population moves online and offline for a variety of reasons—economic and social. The Pew project estimates that only 24 percent of Americans are completely disconnected from the Internet, that is, they have no direct or indirect experience with the Internet, and moreover, are unlikely to have an Internet connection. The rest of the population either has a regular Internet connection or once had a connection and may have one again in the future. Of particular relevance for the target of the Internet access objective is the Pew finding that Internet penetration rates have remained steady since late 2001 at about 60 percent. Although there may have been some optimism a few years ago that the Internet would follow a steadily increasing diffusion curve, this outcome may no longer be likely, particularly at the subpopulation level.

The leveling off of Internet connections occurs at a time of declining prices for devices to connect to the Internet. The costs of computer hardware and software are declining; for example, Internet-ready computers have fallen in price from $1,700 in 1996 to a few hundred dollars in 2003. Declining prices on entry-level computers and other Internet-ready devices may motivate some people to connect to the Internet, but declining prices alone are unlikely to motivate the 40 percent of the population that does not have a household Internet connection. Widespread availability of broadband services through local Internet service providers may bring new users to the Internet but, with the cost of broadband service remaining relatively static and about twice as much as dial-up service, it is equally likely to be an upgrade for those who already have dial-up service. Application developers are continuing to identify ways to attract new users with more attractive content and features. More widespread use of tailoring technologies may make content more attractive and draw new users to the Internet, and current users might increase their interest in being online and the time they spend online.

Along with the increasing speed and power of existing hardware, software, and bandwidth comes the emergence of Internet appliances that will change the way people view technology. As the elements of television, telephone, PCs, game consoles, and entertainment centers begin to merge into multifunctional, single devices, household consumers are likely to view these technologies differently. Those who have an innate fear of computers may connect to the Internet through television or cell phone. Those who cannot afford a stand-alone computer may use game consoles to connect to the Internet. Many of the advances in technology penetration can be linked to new entertainment options, so game consoles that allow multiuser games across the Internet may serve as the impetus for some households to finally get online.

These trends, however, will not necessarily mean access for all. Household penetration does not always provide access for all household members. Nor does it reflect how such access is being used and what benefits or risks result from such use. The following general strategies provide an outline for progress toward meaningful access.

- *Establish and support an ongoing research and evaluation agenda.* There is a need to continue to collect data that will enable us to understand the forces influencing achievement of the objective. Among the factors that should be examined are geographic differences, income, race, gender, and other population characteristics that we may not even know about yet. As we learn more about the factors that influence interest in the Internet, should 80 percent be the universal target? Is it better to try to achieve a national average of 80-percent penetration or to aim for 80-percent penetration for each type and location of household, defined according to relevant characteristics? Targets should continually be monitored and revisited over the next 7 years to ensure that the objective is consistent with technology opportunities and availability. Such a research agenda will guide our capacity to customize solutions to overcome barriers specific to each target audience segment that stand in the way of accomplishing the objective.

- *Develop public and private policies.* An expansion of the principle of universal service to include Internet access to homes would provide important impetus. As currently defined, universal service applies to residential telephone services and select community services. According to the FCC, "the goals of Universal Service, as mandated by the 1996 Act, are to promote the availability of quality services at just, reasonable, and affordable rates; increase access to advanced telecommunications services throughout the Nation; advance the availability of such services to all consumers, including those in low-income, rural, insular, and high-cost areas at rates that are reasonably comparable to those charged in urban areas" (www.fcc.gov/wcb/universal_service/welcome.html).

- *Implement programmatic initiatives.* Continued support is essential for programmatic initiatives directed at overcoming attitudinal, knowledge, skill, and other predisposing factors that represent barriers to acquisition of equipment and connections. Initiatives with demonstrated success should be supported at a level that enables them to grow to scale and serve many more people. Many years have already been spent testing small pilot programs. It is time to take the lessons learned and put them to work. For example, one of the lessons learned is that to make a home access program work, technical support and training for end-users must be addressed. Successful home-access programs also usually engage community-based, trusted intermediaries to organize distribution and technical assistance efforts. Trusted intermediaries are much more likely to persuade people that the Internet is useful, entertaining, and not too difficult to use than are general appeals to the civic, educational, or commercial virtues of the Internet.

Establish and support an ongoing research and evaluation agenda.

- Review and reassess data collection strategies annually.
- Identify appropriate mechanisms for audience segmentation for delivery of programs and incentives.
- Focus on understanding relevant population differences.
- Identify a lead agency with oversight responsibility to coordinate an action plan.
- Identify healthcare providers, businesses, social service agencies, and other public and private-sector entities that would benefit from having their customers or clients connected to the Internet.
- Identify communities in need and their trusted intermediaries who are already using the Internet.
- Identify those individuals and households that are ready to use the Internet and the assistance they need to make it happen.
- Use data from the Health Literacy Component of the 2003 National Assessment of Adult Literacy to identify collaborative strategies to address Internet use and health literacy issues.

Develop public and private policies.

- Identify and analyze Federal, State, and local policies that act as incentives or disincentives.
- Identify and analyze related educational and economic development goals that act as local incentives and disincentives.
- Create model policy guidelines for public and private concerns interested in pursuing such opportunities.
- Engage appropriate intermediaries to influence policy analysis and modification.
- Identify technology champions in the public sectors.
- Provide incentives to homebuilders of public and low-income housing to include infrastructure for Internet access.

- Identify incentives for refurbishing and repurposing computers and other donated equipment.
- Provide incentives for those who are ready and able to acquire access to the Internet from the home.
- Promote discussion about expanding the definition of residential universal service to include Internet service.

Implement programmatic initiatives.

- Identify and analyze Federal, State, and local activities that have been successful in increasing home Internet connection rates.
- Identify and analyze related educational and economic activities to facilitate or provide Internet access.
- Use the literature on help-seeking behavior, diffusion of innovations, stages of change of the Transtheoretical Model, and other related theories as the basis for program activities.
- Convene an ongoing forum for stakeholders to develop a national action plan on home digital inclusion.
- Create model health communication and outreach programs promoting household Internet access.
- Develop a coalition of public groups, government agencies, and the private sector to implement the action plan.
- Support training initiatives that increase skills.
- Use community centers to provide training and model Internet use behaviors that allow potential users to become more familiar and comfortable with technology in the home.
- Examine mechanisms for increasing opportunities for content syndication.
- Identify communities and their connected intermediaries.

LEAD ORGANIZATIONS AND RESPONSIBILITIES

Suggested leads for the research agenda include

- Summarize existing literature (Office of Disease Prevention and Health Promotion [ODPHP]).
- Convene a working group (representative of all stakeholders) to determine new data collection efforts (ODPHP, National

Cancer Institute, and Centers for Disease Control and Prevention).

TIMEFRAME FOR ACTION STEPS

Phase I: Address research issues.

- Within 6 months, re-examine data collection and analysis strategies systematically.
- Within 6 months, develop an evaluation plan for monitoring the effectiveness of activities to influence this objective.
- Within 12 months, develop strategies for population segmentation.

Phase II: Promote discussion about expanding the definition of universal service.

- Within 6 months, develop a plan to promote discussion of residential universal service to include Internet access in the home.

Phase III: Package programmatic initiatives.

- Within 18 to 36 months, identify strategies for leveraging support and building incentives.
- Within 18 to 36 months, focus on sustainable economic and fiscal policies to saturate communities with initial Internet connections.

Eng TR. *The ehealth landscape: a terrain map of emerging information & communication technologies in health and healthcare.* Princeton, NJ: The Robert Wood Johnson Foundation, 2001. Available online at www.rwjf.org/publications/publicationsPdfs/eHealth.pdf.

HarrisInteractive. *Cyberchondriacs update.* May 2002. Available online at www.harrisinteractive.com/harris_poll/index.asp?PID=299.

Harris LM, ed. *Health and the new media: technologies transforming personal and public health.* Mahwah, NJ: Lawrence Erlbaum Associates, 1995.

Ipsos-Reid U.S. Market Research. *The face of the Web.* Washington, DC, 2001.

Lenhart A. *The ever-shifting Internet population: a new look at Internet access and the digital divide.* Washington, D.C.: The Pew Internet and American Life Project, 2003. Available online at www.pewinternet.org/reports/toc.asp?Report=88.

NGA Center for Best Practices. "Digital divide" being creatively bridged in several states. 2001. Available online at www.nga.org/center/frontAndCenter/1,1188,C_FRONT_CENTER%5ED_2188,00.html.

Roberts DF, Foehr UG, Rideout VJ, Brodie M. *Kids media @ the new millenium.* Pub #1536. Menlo Park, CA: Kaiser Family Foundation, November 1999. Available online at www.kff.org/content/1999/1535/KidsReport%20FINAL.pdf.

Science Panel on Interactive Communication and Health. *Wired for health and well-being: the emergence of interactive health communication*, Eng TR, Gustafson DH, eds. Washington, DC: U.S. Department of Health and Human Services, U.S. Government Printing Office, April 1999.

UCLA Center for Communication Policy. *UCLA Internet report 2001—surveying the digital future year two.* November 2001. Available online at http://ccp.ucla.ed.

U.S. Department of Commerce. *Computer and Internet use supplement to the current population survey*, September 2001. Available online at www.bls.census.gov/cps/computer/computer.htm.

U.S. Department of Commerce. *Falling through the net: toward digital inclusion.* Washington, DC: U.S. Department of Commerce, October 2000. Available online at www.ntia.doc.gov/ntiahome/fttn00/contents00.html.

U.S. Department of Commerce. *A nation online: how Americans are expanding their use of the Internet.* Washington, DC: U.S. Department of Commerce, February 2002. Available online at www.ntia.doc.gov/ntiahome/dn/index.html.

Wartella E, O'Keefe B, Scantlin R. *Children and interactive media.* New York: Markle Foundation, May 2000. Available online at www.markle.org/news/digital_kids.pdf.

Web-based Education Commission. *The power of the Internet for learning: moving from promise to practice.* Washington, DC: Web-based Education Commission to the President and the Congress of the United States, 2000. Available online at http://interact.hpcnet.org/webcommission/index.htm.

OBJECTIVE 11-2
IMPROVEMENT OF HEALTH LITERACY

DRAFTER

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TEXT OF OBJECTIVE

Improve the health literacy of persons with inadequate or marginal literacy skills.

SCOPE

The objective is intended to represent an important aspect of health literacy but cannot encompass all issues raised by and related to the subject. The objective means to serve the specific purpose of providing data on progress for health literacy improvement and the general purpose of stimulating discussion about a wide range of health literacy issues.

MEASUREMENT

The objective is developmental and will become measurable with data from the Health Literacy Component (HLC) of the 2003 National Assessment of Adult Literacy (NAAL). The NAAL is administered by the National Center for Education Statistics

(NCES), U.S. Department of Education. The NAAL is the third literacy assessment of American adults. The first assessment of adult literacy, the Young Adult Literacy Survey, was administered in 1985, followed by the National Adult Literacy Survey in 1992. Data from the NAAL, which will be available in late 2004, will be used to establish a baseline and target for the objective and to complete the *Healthy People 2010* data template.

The HLC, which is the first-ever national assessment of health literacy, was jointly developed by the U.S. Department of Health and Human Services (HHS) and the U.S. Department of Education. As the lead agency for the health literacy objective, the Office of Disease Prevention and Health Promotion (ODPHP), HHS, organized a multiagency collaboration to identify stimulus materials and items for the HLC. In addition, ODPHP consulted with established health literacy experts outside the Federal Government about the appropriateness of the selected stimulus materials and items. NCES has overall responsibility to harmonize the HLC with the NAAL.

Currently, the NAAL is scheduled to be fielded only once between 2000 and 2010. If additional measures for the decade are required, either the NAAL will need to be re-administered or a different instrument will need to be identified.

The NAAL and its predecessors assess functional literacy—that is, people's ability to apply reading skills to everyday tasks involving prose, documents, and numbers. The mundane tasks include reading a newspaper, filling out an employment form, reading a bus schedule, adding a bank account entry, or computing a tip in a restaurant. Skills are measured against commonly used materials in society. The HLC of the 2003 NAAL will similarly focus on functional literacy; health-related activities, part of adults' typical experiences, will be incorporated into the functional literacy assessments. The NAAL will provide data on the percentage of persons with inadequate or marginal literacy skills who can perform specific health literacy tasks.

The HLC includes three types of health information and services: clinical, prevention, and navigation of the healthcare system. They are key types of health and healthcare information and services that the general population in the United States might be likely to encounter. The stimulus materials and the associated items in the HLC were selected to fit these types.

- The **clinical type** includes those activities associated with interactions between the healthcare provider and the patient, clinical encounters, diagnosis and treatment of illness, and medication. Examples include filling out a patient information form for an office visit, understanding dosing instructions for medication, understanding steps for the self-management of acute and chronic illness, following a healthcare provider's recommendation for a diagnostic test, and providing accurate information in a medical history, either verbal or written.
- The **prevention type** includes those activities associated with maintaining and improving health, preventing disease, intervening early in emerging health problems, and engaging in self-care and healthy behaviors. Examples include following guidelines for age-appropriate preventive health services, identifying signs and symptoms of health problems that should be addressed with a health professional, and changing eating and exercise habits to decrease risks for the development of serious illness.
- The **navigation of the healthcare system type** includes those activities related to understanding how the healthcare system works and individual rights and responsibilities. Navigation requires being familiar with the vocabulary, concepts, and processes needed to use the healthcare system. Examples include understanding covered and noncovered benefits for health insurance plans, determining eligibility for public assistance programs, and being able to give informed consent for a healthcare service.

The question has been raised as to whether the objective should be reworded as a population objective so that data on the health literacy skills of the entire U.S. population, instead of only those with marginal or inadequate literacy skills, would be measured and reported.

The objective was formulated as an assessment of individuals' health literacy skills. Individuals' skills, however, are only one part of the complex health literacy phenomenon. Healthcare providers, creators of health information and education materials, and the healthcare and public health systems bear a large part of the responsibility for having created materials, ways of communicating, and systems that are far too technical and complicated to meet the needs of the vast majority of the populations they serve. Consequently, the burden for change, at least in the short term, lies with healthcare providers, public health professionals, and healthcare and public health systems, in partnership with adult literacy programs, to reach those with limited literacy. Long-term, educational programming can work to raise the general literacy levels of the population and to incorporate training in navigating health systems. Any assessment of individuals' health literacy skills, therefore, must be interpreted in light of the systemic factors that strongly influence individuals' capacity to demonstrate health literacy.

Shame associated with poor literacy skills may be an important factor in obtaining an accurate account of the population's health literacy skills. Individuals with poor literacy skills are often very uncomfortable that they cannot read well, and they develop strategies to compensate. Depending on the method of assessment, individuals may use these strategies to appear to have higher literacy skills than they actually do.

The assessment of health literacy in a population is also influenced by the reading levels of health materials, the skills of individuals, the communication abilities of health professionals, and the organization of delivery systems for health information and services. Although the literacy and verbal skills of individuals are of critical importance, so too are the demands made by the health materials themselves, the communication skills of those in the health field, and the complicated nature of the healthcare and public health systems. The dimensions of these additional factors are briefly examined in the following.

- *Functional literacy measures incorporating currently available health materials do not offer a sufficient assessment of health literacy.*

  The NAAL's health literacy measures will be based on common, widely used health information materials. However, three decades of studies published in medical and public health journals indicate that most health materials fall into reading-level ranges requiring high school, college, or graduate degrees (Rudd, Moeykens, and Colton, 1999) and often contain jargon and scientific terms rather than everyday or plain language. Additional measures will be needed to monitor improvements in the format, content, and structure of health materials prepared for the public. The current reading level and demands of health-related materials should be compared with rewritten and newly formatted materials over time.

  Most currently used assessment tools are designed for examinations of prose materials presented in sentence and paragraph format. However, a good deal of health-related print materials are prepared in document format using phrases, lists, and bullets rather than full sentences and paragraphs. Published studies of health materials suggest that health researchers have not applied the document assessment tool developed by Mosenthal and Kirsch (1998).

  Many critical health-related materials are written in open-entry format (e.g., medical history forms, insurance forms, in-take forms, research queries). The field would benefit from the development of assessment measures and open-entry format for health documents.

- *Health literacy assessments are too narrowly focused on the ability of individuals to use the written word.*

  Linguists and reading experts have established links among a variety of skills such as reading, verbal presentation, and oral comprehension (Snow, 1991; Cunningham and Stanovich, 1998). In medical care settings, patients are expected to offer health histories and descriptions of symptoms and to listen to and comprehend verbal instructions. Adults are expected to understand, navigate, and meet the demands of bureaucracies and institutions to access entitlement programs and services. In the community, adults are encouraged to be aware of and act on health-related news and announcements. Each of these settings presents its own set of health literacy demands and requires different mixes of skills, which should be assessed.

Health communications routinely include written as well as audio and video materials, messages on radio and television, and verbal presentation for information, diagnosis, and consent. An expanded examination of health-related materials must include information presented on tapes, videos, compact discs, and the Web (Stauffer et al., 1978; D'Alessandro et al., 2001). Research is also needed to assess how easily these different materials are used by low-literate populations and how well they can understand messages in these formats.

- *Health professionals' skills and the burdens of medical jargon, technical language, and complicated bureaucratic processes affect health literacy.*

Patients' ability to understand health and medical issues and directions is related to the clarity of the communication. Consideration needs to be given to the verbal as well as written communication skills of medical and public health practitioners. Factors of class, age, race, ethnicity, country of origin, gender, geography, health status, and (because family members may be part of the healthcare episode) family dynamics and roles may affect how patients interact with their healthcare providers and their ability to take actions to improve their health.

Official documents, including informed consent forms, social services forms, and public health and medical instructions, as well as health information materials often use jargon and technical language that make them unnecessarily difficult to use. Reductions in the assessed reading levels of forms, instructions, and informational materials are insufficient. The amount of jargon and technical language could be reduced with greater adoption of plain language.

- *Special consideration should be given to the conduct of health literacy assessments of persons with limited proficiency in English.*

Assessments of health literacy for those with limited proficiency in English have some special challenges. Limited proficiency in English may make it difficult if not impossible for individuals to complete a health literacy assessment in English. Translation of the assessment into native languages is often not an adequate solution. Translators are typically from a different social class and speak different dialects or even languages than poor and working class individuals who are most frequently those with limited proficiency in English. In addition, limited proficiency in English is itself a barrier to accessing many types of health information and services, and, consequently, individuals may not have enough experience with a broad spectrum of health information and services to complete a standard health literacy assessment in English or their native language. Translation also is not an adequate solution because individuals may have limited literacy and oral communication skills in their native languages. Even translated materials may be too complex in presentation, writing style, and vocabulary for individuals with low levels of functional literacy in both English and their native languages.

- *Culturally based understandings of health and health care are relevant to the conduct of functional health literacy assessments.*

In addition to the assessment challenges presented by limited proficiency in English, cultural and linguistic considerations must be accounted for. Understanding the relationships among culture, language, and health is critical for the design and conduct of health literacy assessments in a multicultural society. According to the Office of Minority Health, HHS, culture and language may affect health, healing, and wellness belief systems; how illness, disease, and their causes are perceived; the behaviors of individuals seeking health care; and the delivery of healthcare services and provider behavior. Even if assessments of health literacy are conducted in the appropriate language for a specific population, instruments that are not sufficiently sensitive to cultural and linguistic differences may mischaracterize a population's ability to comprehend and act on critical health information and service recommendations.

- *Systemic factors affect individuals' health literacy skills.*

  Healthcare and public health delivery systems are complicated bureaucracies with many procedures and processes associated with obtaining health care and public health services. Patients, clients, and their family members are typically unfamiliar with these systems and the associated jargon. Even highly motivated and educated individuals may find the systems too complicated to understand, especially when persons are made more vulnerable by poor health. Consequently, assessments of individuals' health literacy skills may actually reflect systemic complexity rather than individual skill levels. Studies of the complexity of healthcare and public health systems need to supplement and inform any assessments of individuals' health literacy skills.

Definition of Terms

Measures of health literacy must be based on clear articulation of terms, a selection of representative health-related activities, and a delineation of needed skills.

- *Functional literacy.* The National Literacy Act of 1991 (National Institute for Literacy, 1991) offered the following definition of literacy:

> For purposes of this Act, the term "literacy" means an individual's ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential.

- *Health literacy. Healthy People 2010* (HHS, 2000) cites and applies the following definition of health literacy:

> The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Various other definitions of health literacy have been proposed. Researchers note that health literacy must be understood as a dynamic characteristic that ebbs and flows in response to other factors, including health materials, communication skills of those delivering the message, changes in life experience, education, and the presence of comorbid conditions such as depression, mental illness, and functional status. Functional health literacy must also be understood in terms of having multiple antecedents or confounders. They include not only obvious factors such as educational attainment but also factors such as dyslexia, social deprivation, and mental illness.

STATE OF KNOWLEDGE ABOUT ISSUES REPRESENTED BY THE OBJECTIVE

Education, traditionally used as a marker of socioeconomic status in the United States, has long been linked to health outcomes (Pamuk et al., 1998). Until recently, few inquiries had looked more closely at factors associated with education such as literacy. Health literacy, now squarely on the health agenda, emerged during the 1990s. Now, evidence is accumulating that persons with limited literacy are at risk for poor health outcomes.

Most medical and public health publications focused on literacy in the United States comprised findings from studies examining the reading level of print materials developed for patient education and for procedures and processes in healthcare settings (Rudd and Colton, 1998). Overall, researchers firmly established that the literacy demands of health materials exceeded the reading abilities of the average U.S. adult. Unique among the early health literature was a review article on health literacy in the 1989 *Annual Review of Public Health*, highlighting links between literacy and health outcomes. Based on research conducted in developing countries, Gross and Auffrey (1989) presented a body of evidence that the health of children was related to the literacy of their mothers. The findings noted in the annual review and the subsequent analysis of the National Adult Literacy Survey in 1993 spurred interest in the links between literacy and health outcomes in the United States.

The use of reading assessment tools in clinical settings and the development and use of the health-specific Rapid Estimate of Adult Literacy Measure (REALM) (Davis et al., 1991) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995) provided tools for health researchers interested in exploring these links. First, researchers were able to specifically compare the reading level of the health materials with the reading ability of members of the intended audience. Initial studies highlighted patients' difficulty in reading and understanding screening materials, appointment slips, directions for medicines, and informed consent documents. These studies more firmly established the disparities between the demand of health materials and the abilities of the people for whom the materials were developed, which had been noted in the publications of the 1970s and 1980s. In addition, researchers were now able to use these tools to examine health outcomes among patients with differing literacy skills.

A sparse but growing body of literature published during the mid- to late 1990s includes studies focused on the differences between various health-related measures in adults with limited literacy skills and those with literacy skills at or above the ninth grade level. For example, patients with low literacy report poorer health than do patients with high literacy (Weiss et al., 1992). They are less likely to make use of screening (Davis, Berkel, Arnold, et al., 1998), are more likely to present in later stages of disease (Bennet et al., 1998), and are more likely to be hospitalized (Baker et al., 1998). Numerous studies (Rudd et al., 2000) show that low literacy has been associated with poor health, poor understanding of treatment, greater use of health services, and low adherence to treatment regimens (a selection of studies are noted in the references). Finally, at the end of the decade, the American Medical Association's Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs (1999) published a white paper reflecting medicine's growing recognition of literacy and its role in health. An increasing number of national and international meetings on health literacy highlighted a growing recognition of the importance of literacy to those in the health fields.

Overall, the interest in health literacy has focused more on healthcare settings than on health actions and decisions at home, in the community, in the workplace, or in the policy arena. The published literature offers little evidence that public health practitioners have adequately met the challenges of limited literacy skills among populations of interest. The relationship between literacy and health promotion, health protection, and disease prevention activities has not been fully explored. For example, only one or two studies and reports have examined literacy and its relation to the purchase and use of food and home products, decisions involved in insurance and service delivery care options, or action related to occupational health and safety. Literacy links to health outcomes related to the care of children or elders, participation in community-based health action groups, or policy decisions have not been established. Little is known about how many individuals are lost to or excluded from health-related public assistance programs because of their limited literacy skills or because of inappropriately constructed documents, forms, and demands. Furthermore, few studies have examined health literacy links from the perspective of social justice and links to human rights; however, several studies have examined the informed consent process over time (Raich et al., 2001).

STAKEHOLDERS

Organizations currently working on health literacy or related issues include, but are not limited to, the following:

- AARP
- Academy of General Dentistry
- Ad Council
- Adult Literacy Media Alliance
- AMC Cancer Research Project
- American Association of Medical Colleges
- American Hospital Association
- American Medical Association
- American Medical Association Foundation
- American Nurses Association
- American Occupational Association
- American Pharmaceutical Association

- American Physical Therapy Association
- American Public Health Association
- Center for Medicare Education
- Hudson River Center for Program Development
- Institute of Medicine
- International Literacy Network
- Joint Commission on Accreditation of Healthcare Organizations
- Latino Health Institute
- Maine AHEC Health Literacy Center, University of New England
- Managed Care Consumer Assistance Program, Community Service Society of New York
- Massachusetts Department of Education: Operation Bootstrap, The Literacy Project, Read, Write, Now
- Moffitt Cancer Center and Research Institute
- National Academy on an Aging Society
- National Association of Broadcasters
- National Association of Science Writers
- National Cancer Institute
- National Center for the Study of Adult Learning and Literacy
- National Committee for Quality Assurance
- National Health Council
- National Institute for Literacy
- NVision (new adult literacy campaign)
- Pfizer Corporation
- Society of Professional Journalists
- State Adult Education Programs Integrating Health Literacy (California, Georgia, Massachusetts, New Hampshire, Pennsylvania, Vermont, and Virginia)
- State Health Literacy Coalitions (California, Maine, Massachusetts, New Hampshire, Ohio, Pennsylvania, and South Carolina)

- The Robert Wood Johnson Foundation
- U.S. Department of Defense, Tricare
- U.S. Department of Education
- U.S. Department of Health and Human Services (including Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, Indian Health Service, National Institutes of Health, and Office of Disease Prevention and Health Promotion)
- U.S. Department of Labor
- U.S. Department of Veterans Affairs, Veterans Health Administration
- World Education

Potential: Additional stakeholders should be identified; they would include agencies and organizations addressing health disparities as well as labor, industry, and environmental organizations.

STATUS OF SELECTED STAKEHOLDER ACTIVITIES

A number of States have recently launched health literacy initiatives (Matthews and Sewell, 2002). Presentations at national organizations have increased. To date, however, few stakeholders have actively funded health literacy research or implementation initiatives. Several Web sites, conference reports, and other publications have reported on the status of health literacy-related activities. For example:

- Health and Literacy Compendium, World Education, and National Institute for Literacy
- Health Literacy Proceedings, published and distributed by Pfizer, Inc.
- An initiative on health literacy, launched by the American Medical Association Foundation, to raise physicians' awareness of the issues.
- Forthcoming evidence-based practice review, sponsored by the Agency for Healthcare Research and Quality, HHS

- Forthcoming report from the Committee on Health Literacy, Institute of Medicine
- Ongoing research, National Institutes of Health, HHS

FACTORS THAT CAN INFLUENCE CHANGE

Barriers to Change

Some of the multiple barriers to change are noted below:

- Poverty as well as minority and immigrant status are associated with limited literacy skills. The effects of literacy, income, poverty, and health are related and interdependent.
- As noted in the section on issues related to measurement, limited proficiency in English and cultural and linguistic differences present important challenges and likely barriers for individuals and populations to receive appropriate health information and services.
- Practitioners, researchers, or funding agencies in the public health and healthcare fields may be unaware of findings of functional literacy assessments of adults.
- Reading, writing, and presentation skills are finely tuned in institutions of higher learning but are geared for dialog and discussion among members of highly educated and often specialized audiences. Plain language communication may be considered a new skill.
- Although public health and medical practitioners work to increase awareness and provide information, neither field has assumed the task of fully educating the public about how the body functions, health research findings, health information, and the environment.
- Many interventions aimed at low-literacy populations have been developed and implemented; however, little has been done to evaluate the effectiveness of these interventions in terms of meaningful long-term health outcomes.
- The process of delivering healthcare information, whether oral or written, does not typically include a method to determine whether the information is understood by the recipient.

Leverage Points

Leverage points for actions that have worked or have potential to effect change are described below:

- Federal and State legislation that promotes health literacy can effect change.
- Research findings linking functional literacy to health status provide critical leverage points for action.
- Costs associated with incorrect use of medications, failure to comply with medical directions, and safety risks in workplaces can be used to support changes in policies.
- Government regulations, such as plain language requirements, can substantially effect changes in materials.
- Legal action provides leverage points for change. To date, a few court decisions have been related to the literacy of clients or patients or the reading level of the materials—for example, see Wong (1998).
- National initiatives to effect change include Leave No Child Behind, Plain Language, White House Initiative on Hispanics (and Immigrant Populations), Centers for Medicare & Medicaid Services campaign to improve communication with Medicare beneficiaries, Agency for Healthcare Research and Quality efforts to improve patient safety, and the Government Performance and Results Act.
- Research and interventions in the field of health communication have improved communication between patients and providers.
- Earlier diagnosis of reading and language disabilities would permit earlier interventions.

STRATEGIES AND SOLUTIONS

All of the proposed strategies and solutions depend on building increased awareness of the magnitude of health literacy problems in the United States and on identifying systemic changes that will make U.S. health systems easier for individuals to understand and use. A critical link among literacy, health, and health status must be recognized at a broad societal level. Ensuring health literacy in the United States is a fundamental issue of fairness and basic human rights. No single public or private entity can improve the health literacy of individuals. Partnerships, both traditional and new, will be required to marshal the necessary resources to make progress on health literacy. Each population or stakeholder group needs to engage in skill-building to address both the supply side (e.g., those who create health messages, information, forms, and documents; those who staff the healthcare, public health, and health education systems) and the demand side (e.g., patients, clients, their families and caregivers, consumers). Stakeholders are likely to realize the benefits from health literacy improvements by way of improved communication, greater adherence to treatment regimens, greater ability to engage in appropriate self-care, improved health status, and greater efficiency and cost savings to the health system as a whole. Health literacy, therefore, is relevant not only as a single objective but as an element of all the *Healthy People 2010* objectives.

ACTION STEPS

Develop a national focus and agenda for health literacy.

- Convene an exploratory planning committee to assess the opportunities for a national conference, such as a White House Conference on Literacy with health literacy as a major component or a separate White House Conference on Health Literacy.
- Convene a working group to collaborate on a national report on health literacy based on data from the 2003 *National Assessment of Adult Literacy.*

Change professional practice for healthcare providers and public health professionals, including health educators.

- Encourage professional organizations to make health literacy issues a high priority on their policy, research, and practice agendas and to develop positions and issue policy statements and papers.
- Secure commitments from professional organizations to become involved in health literacy issues and advocate for change.

- Encourage and support effective communication skills of health professionals, including the development of curricula for health professional training and continuing education.
- Engage the media to increase professional and public awareness of the issues.
- Connect health literacy issues to ongoing efforts to improve the cultural competence of healthcare providers.
- Emphasize and support health communication efforts that address the needs of low-literate populations.
- Promote the use of plain language and encourage widespread development and use of health glossaries.
- Encourage health practitioners to work with adult educators on the delineation of needed skills to support health literacy rather than on the transfer of health information. Adult education professionals have long focused on skill-building activities related to language and vocabulary acquisition, reading, writing, numeracy, oral comprehension, and discussion. Their expertise can support and enhance health literacy goals.
- Develop and implement educational curricula in professional and continuing education programs.

Partner with adult education to improve literacy skills.

- The adult education sectors within several States have launched health literacy initiatives (Matthews and Sewell, 2002). Adult education curricula have frequently included health lessons often related to hygiene, nutrition, healthful or harmful habits, and substance use. Two national surveys indicated that State directors and adult education teachers believed that health-related content would likely engage adult students and thereby increase learner interest, motivation, and persistence (Rudd and Moeykens, 1999; Rudd, Zahner, and Banh, 1999). Health practitioners working with adult education systems gained access to and communicated with adults not reached through traditional health outreach. Thus, adult education learning centers provided the health field with an ideal site for reaching poor, minority, and medically underserved populations. At the same time, teachers and directors were cautious about the appropriateness of asking adult education teachers to present lessons on health content, which is not, after all, their area of expertise. However, adult education systems, with the goals of building skills for full participation in society, could augment students' abilities to access and navigate the difficult pathways of health information for themselves, their families, and their communities.

Enhance access to health information.

Materials

- Collect comprehensive baseline data on the clarity of existing health information materials.
- Assess the readability of both prose and document health materials.
- Simplify and clarify health information in both prose and document forms.
- Evaluate the effectiveness of simplified health information.
- Promote the use of plain language and encourage widespread development and use of health glossaries.
- Promote the development of materials that are culturally and linguistically appropriate.
- Evaluate the effectiveness of improving health literacy on healthcare outcomes and health status.
- Develop best practices for health literacy.
- Develop resources of patient education materials written in plain language that can be easily available to health professionals.

Media

- Increase the media's awareness of health literacy issues and audience needs.
- Work with the media to make scientific information easier to understand for all types of audiences.

Oral and other nonwritten forms of communication

- Establish a baseline of oral communication.
- Improve understanding of what is effective oral communication.
- Promote the use of culturally and linguistically appropriate communication in oral and other nonwritten forms of communication.
- Adapt best practices from written communication to all other forms of communication, including oral, signed, audio, visual, and alternative or assistive devices.

Collaboration among all professional groups

- Adult education
- Reading specialists
- Mass media
- Minority news organizations
- Health communicators
- Plain language specialists
- Healthcare providers
- Healthcare organizations and health plans
- Public health professionals
- Legal and regulatory experts

Enhance access to health services delivery system (e.g., surveys, forms, questionnaires, signs, and other explanatory materials in healthcare locations).

- Assess the legal requirements of existing forms to determine how they can be simplified and rewritten within those requirements.
- Develop appropriate tools to assess the comprehension of forms and other materials used in healthcare delivery.
- Collect comprehensive baseline data on the comprehensibility of existing forms and other materials.
- Use findings to simplify and clarify forms and other materials.

- Increase the number of ombudsmen in healthcare facilities and enhance their roles to include assisting patients, clients, and their families and caregivers with literacy demands.

Support the adult education system, including literacy programs at work, in correctional facilities and job training, family literacy, and ESL and distance learning programs.

- Promote the expanded availability of adult education programs, particularly in worksite and healthcare settings.

Support all forms of literacy skill development for all population groups (e.g., age 0 to 3 years, preschool, K–12, adult, family).

- Expand and strengthen interventions after initial diagnoses for reading and language disabilities.
- Increase funding and program availability for document and numeracy skill training.

Include health literacy as a fundamental consideration in health policy and program planning.

- Identify financial constraints, such as lack of reimbursement for patient education, in the healthcare system.
- Initiate cost-benefit studies examining the relationships among health literacy, health status, and healthcare system costs.
- Provide incentives for recipients of publicly funded grants, contracts, cooperative agreements, and program funds to demonstrate how they address the health literacy needs of the populations studied or served.
- Identify any needed regulations and appropriate agencies to monitor compliance.
- Promote additional research, including formative research, and program funding to address health literacy needs.
- Promote the use of plain language. The Canadian Public Health System has adopted plain language rules that may provide a model.
- Expand definitions of at-risk population groups to include people without a high school diploma or with limited literacy skills.

Engage community organizations and the lay public in health literacy efforts.

- Inform the lay communication network through community development approaches.
- Encourage participatory health and education efforts.
- Work with adult educators to develop communication skills broadly.

Skill-building related to forms, directions, and information packets is important but will not suffice. Activities such as becoming aware of new findings, gathering information, and participating in community- or work-related action groups require efficacy-building and skills related to research, discussion, analysis, decisionmaking, and action. Many of these broader communication skills are already being taught in some adult education programs. Health-related curricula incorporating attention to these skills can enrich adult learners' experiences and will support health literacy goals.

Enhance health literacy research and its translation into practice.

- Support studies of effective communication tools and techniques. The American Medical Association's (AMA's) Ad Hoc Committee on Health Literacy identified only 38 published articles that discussed how to communicate with low-literacy populations. Of these, only 17 discussed the development or implementation of interventions to improve patients' knowledge or outcomes, of which only one was a randomized, controlled trial.
- Emphasize, support, and study nonprint communication efforts.
- Create standards for the use of nontraditional media.
- Develop and apply new markers for quality effective communication.

LEAD ORGANIZATIONS AND RESPONSIBILITIES

Examples: AMA and the AMA Foundation are working to increase awareness of health literacy among physicians and other health professionals through the distribution of health literacy kits and materials and a campaign on health literacy to reach medical societies, medical schools, conferences, group practices, and hospitals. Led by Pfizer, Inc., a number of national organizations have recently joined together to launch a program to educate consumers and patients about how to communicate better with their healthcare providers.

TIMEFRAME FOR ACTION STEPS

National conference on health literacy: 3 to 5 years

FOR MORE INFORMATION

Canadian National Adult Literacy Database
www.nald.ca

Health Literacy Literature
www.nlm.nih.gov/pubs/cbm/hliteracy.html
www.hsph.harvard.edu/healthliteracy

International Adult Literacy Survey
www.statcan.ca/english/freepub/89-552-MIE/free.htm

Literacy and the Web
www.usability.gov
www.cast.org/bobby

National Adult Literacy Survey
http://nces.ed.gov/naal

National Center for the Study of Adult Learning and Literacy
http://ncsall.gse.harvard.edu

National Institute for Literacy
www.nifl.gov

National Partnership for Reinventing Government
www.plainlanguage.gov

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. Health literacy: report of the Council on Scientific Affairs. *J Am Med Assoc* 1999;281:552-7.

Baker DW, Parker RM, Williams MV, et al. The healthcare experience of patients with low literacy. *Arch Fam Med* 1996; 5:329-34.

Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. *J Gen Intern Med* 1998; 13:791-8.

Bennett CL, Ferreira MR, Davis TC, Kaplan J, Weinberger M, Kuzel T, Seday MA, Sartor O. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *J Clin Oncol* 1998;16,3101-4.

Cunningham AE, Stanovich KE. What reading does for the mind. *Am Educ* 1998;22:8-15.

D'Alessandro DM, Kingsley P, Johnson-West J. The readability of pediatric patient education materials on the World Wide Web. *Arch Ped Adol Med* 2001;155(7):807-12.

Davis TC, Crouch MA, Wills G, Miller S, Abdehou DM. Rapid assessment of literacy levels of adult primary care patients. *Fam Med* 1991;23(6):433-5.

Davis TC, Michielutte R, Askov EN, Williams MV, Weiss BD. Practical assessment of adult literacy in healthcare. *Health Educ Behav* 1998;25:613-24.

Davis TC, Berkel HJ, Arnold CL, Nandy I, Jackson RH, Murphy P. Intervention to increase mammography utilization in a public hospital. *J Gen Intern Med* 1998;13;230-3.

Davis TC, Fredrickson D, Arnold C, Murphy P, Herbst M, Bocchinni J. A polio immunization pamphlet with increased appeal and simplified language does not improve comprehension to an acceptable level. *Patient Educ Counsel* 1998;33:25-37.

Davis TC, Holcombe RF, Berkel HJ, Pramanik S, Divers SG. Informed consent for clinical trials: a comparative study of standard forms versus simplified forms. *J Nat Cancer Inst* 1998;90:669-74.

Delp C, Jones J. Communicating information to patients: the use of cartoon illustrations to improve comprehension of instructions. *Acad Emer Med* 1996;3:264-70.

Doak CC, Doak LG, Root J. *Teaching patients with low literacy skills*, 2nd ed. Philadelphia: JB Lippincott, 1996.

Grosse RN, Auffrey C. Literacy and health status in developing countries. *An Rev Pub Health* 1989;10:281-97.

HHS. *Healthy People 2010.* 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

Kirsch I, Jungeblut A, Jenkins L, Kolstad A. *Adult literacy in America: a first look at the results of the National Adult Literacy Survey.* Washington, DC: National Center for Education Statistics, U.S. Department of Education, 1993.

Matthews T, Sewell J. *State official's guide to health literacy.* Lexington, KY: Council of State Governments, 2002.

Michielutte R, Bahnson J, Dignan MB, Schroeder EM. The use of illustrations and narrative text style to improve readability of a health education brochure. *J Cancer Educ* 1992;7:251-60.

Mosenthal PB, Kirsch IS. A new measure for assessing document complexity: the PMOSE/IKIRSCH document readability formula. *J Adoles Ad Lit* 1998;41(8):638-57.

National Institute for Literacy. *Public Law 102-73, The National Literacy Act of 1991, July 25, 1991.* Available online at www.nifl.gov/public-law.html.

National Work Group on Literacy and Health. Communicating with patients who have limited literacy skills: report of the National Work Group on Literacy and Health. *J Fam Prac* 1998;46:168-76.

Pamuk E, Makuc D, Heck K, Reuben C, Lochner K. *Socioeconomic status and health chartbook.* Hyattsville, MD: National Center for Health Statistics, 1998.

Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med* 1995; 10:537-41.

Raich PC, Plomer KD, Coyne CA. Literacy, comprehension, and informed consent in clinical research. *Can Invest* 2001; 19(4):437-45.

Roberts P, Fawcett G. *At risk: a socioeconomic analysis of health and literacy among seniors.* Statistics Canada: Human Resources Development Canada and National Literacy Secretariat, 1998.

Rudd RE, Colton T. *An overview of medical and public health literature addressing literacy issues: an annotated bibliography.* Cambridge MA: Harvard Graduate School of Education, 1998.

Rudd RE, Colton T, Schact R. *An overview of medical and public health literature addressing literacy issues: an annotated bibliography.* Cambridge MA: Harvard Graduate School of Education, 2000.

Rudd RE, Moeykens BA. *Adult educators' perceptions of health issues and topics in adult basic education programs.* Cambridge MA: Harvard Graduate School of Education, 1999.

Rudd RE, Moeykens B, Colton T. Health and literacy: a review of the medical and public health literature. *Ann Rev Ad Learn Lit.* San Francisco: Jossey-Bass, 1999.

Rudd RE, Zahner L, Banh M. *Findings from a national survey of State directors of adult education.* Cambridge MA: Harvard Graduate School of Education, 1999.

Snow CE. The theoretical basis for relationships between language and literacy in development. *J Res Child Ed* 1991;6(1):10.

Stauffer J, Frost R, Rybolt W. Literacy, illiteracy, and learning from television news. *Comm Res* 1978;5:221-32.

Weiss B, Hart G, McGee DL, D'Estelle S. Health status of illiterate adults: relation between literacy and health status among persons with low literacy skills. *J Am Board Fam Practice* 1992;5:257-64.

Weiss BD. Identifying and communicating with patients who have poor literacy skills. *Fam Med* 1993;256:369-70.

Weiss BD, Coyne C. Communicating with patients who cannot read. *New Engl J Med* 1997;337:272-4.

Wong, DW. Judge blocks State cutoff of welfare disability aid. *Boston Globe*, December 31, 1998.

OBJECTIVE 11-3
RESEARCH AND EVALUATION OF HEALTH COMMUNICATION PROGRAMS

DRAFTER

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TEXT OF OBJECTIVE

Increase the proportion of health communication activities that include research and evaluation.

SCOPE

The objective is intended to represent an important aspect of the assessment of health communication activities but cannot encompass all issues raised by and related to the subject. The objective means to serve the specific purpose of providing data on progress for research and evaluation of a subset of health communication activities and the general purpose of stimulating discussion about a wide range of health communication research and evaluation issues.

MEASUREMENT

The objective is developmental. Currently, no mechanisms are available to define or measure the total number of health communication activities conducted in the United States. Also, no broad-based consensus has been reached regarding which criteria should be used to determine if an activity includes research and evaluation components.

Any data source would have to specify the universe of health communication activities that should have research and evaluation components (the denominator) as well as the actual number of health communication activities that involve research and evaluation (the numerator). The members of the action plan group determined that the short-term goal should be the measurement of research and evaluation within federally funded communication activities, or even more narrowly, U.S. Department of Health and Human Services- (HHS-) funded communication activities. The long-term goal should be to identify and target for improvement those health communication programs that have not typically been expected to include research and evaluation, including programs run by non-HHS agencies. Research and evaluation should become a standard element not only for federally funded research grants to investigators but also for all funded programs, especially service programs at the community level.

ISSUES PERTAINING TO MEASUREMENT

Data collection and analysis efforts in support of measuring this objective are not an integral part of any stakeholder's mission or mandate. Although stakeholders are active in encouraging research and evaluation in health communication initiatives, they do not have dedicated resources for systematically or routinely collecting data about the number of health communication initiatives that do or do not include research and evaluation activities.

STATE OF KNOWLEDGE ABOUT ISSUES REPRESENTED BY THE OBJECTIVE

The objective is stated broadly enough to encompass any type of health communication activity. The unifying idea is that relevant activities would be strategic and be designed to "inform and influence individual and community decisions that improve health" (Freimuth et al., 2001). Examples of these activities include one-on-one physician counseling of an individual patient, print health information materials for specific diseases or conditions distributed by public health departments, public relations efforts to place health issues on the public agenda, mass media "edu-tainment" with health themes, and national public health information campaigns. For the purposes of the objective, "activity" is synonymous with "intervention" and all that is implied in terms of purposefulness and articulated goals, audiences, methods, and outcomes. Change in health behaviors and social context may occur by other pathways. In a recent compilation of evaluations of public health communication, Hornik (2002) argues that "intervention" may be too narrow a concept to understand change and that public health communication would do equally well to begin with effects. He states,

> The process might start with trying to understand the extraordinary secular trends in some health behaviors that are already in place. There have been some extraordinary changes in smoking and other cardiovascular risk behaviors, in sexual risk behaviors, and in others. Rather than starting with an intervention and its evaluation, health communication research might sometimes start with its effects, the substantial secular change in behavior, and try to explain it.

The scope of the objective does not preclude such a starting point. Rather, in recognition of the limitations imposed by the need to measure progress as well as provide data on strategic investments of publicly funded programs, the objective seeks to promote meaningful research and evaluation as a means to improve the quality of interventions. Research and evaluation of any type that will provide better data and richer explanations of the "messy treatment" of public communication are welcome. At the same time, when interventions are standard features of health communication, the objective focuses attention on research and evaluation as essential components of a sound intervention. Furthermore, research and evaluation should be used to influence all phases of an intervention, including design, implementation, adoption, and redesign.

There is increasing need to focus on the outcomes and effectiveness of any type of health intervention, whether it is communication, biomedical, or some other type. Scarce resources force the issue of "getting our money's worth." Policymakers want to know and program planners need to explain if an investment in a particular intervention was worth it, however the intervention goals are defined. At the same time, scarce resources indicate that program planners and implementers may be reluctant to take away from the actual activity to fund research and evaluation that may be perceived as not directly serving intended audiences.

Evaluation may be perceived as the domain of academic researchers and too expensive; program implementation may be seen as weakened because of the drain of resources for evaluation activities. Often different individuals are responsible for different parts of a program, and there may be a lack of understanding and operational integration of the overall project to assess accurately how resources should be assigned. Lack of integration among planning, implementation, and evaluation "teams" can result in evaluations receiving too little or too much funding to provide the data needed to understand why change did or did not occur.

Information on how to conduct research and evaluation of health communication interventions of various types is abundant. Research and evaluation findings, however, are not always easily available, and consensus is not necessarily reached regarding what needs to be evaluated and how extensive evaluation should be. One challenge in agreeing on what needs to be evaluated relates to the number of different disciplines involved in health communication research. Evaluations of health communication programs are published in many disciplines (e.g., communication, marketing, health education, psychology, journalism/mass media), so finding relevant articles can be difficult. Also, the published literature represents only a fraction of the research that is done: much of the qualitative research conducted for program development is never published. Some of this has to do with the findings not being generalizable, but some of this has to do with the voluminous data that come from qualitative research. Synthesizing data and findings from multiple studies would be an important step in making research and evaluation findings more useful to various audiences and building consensus on the key evaluation factors. The Centers for Disease Control and Prevention (CDC) is currently updating its Internet-based health communication research database (www.cdc.gov/od/oc/hcomm) to help practitioners access the published literature.

STAKEHOLDERS

Organizations actively encouraging systematic research and evaluation of health communication activities include the following: Federal agencies (specifically, CDC, National Cancer Institute [NCI], Office of Disease Prevention and Health Promotion [ODPHP], and National Heart, Lung, and Blood Institute); public health professional organizations (e.g., the American Public Health Association's *Healthy People 2010* Committee of the Health Communication Working Group, the National Public Health Information Coalition, the Society of Public Health Educators); communication professional organizations (e.g., National Communication Association, International Communication Association); social marketing professional organizations (e.g., Institute for Social Marketing); philanthropic foundations (specifically, The Robert Wood Johnson Foundation and WK Kellogg Foundation); numerous private, for-profit, and not-for-profit social marketing firms (e.g., Academy for Educational Development, Prospect Center); and health information creators and providers (e.g., Healthwise, a creator and provider of print and electronic health information).

ODPHP convened a meeting of communication research and evaluation experts on October 18, 2000, to discuss measurement of health communication research and evaluation.

The American Public Health Association's *Healthy People 2010* Committee of the Health Communication Working Group has convened a group to discuss and offer recommendations to ODPHP regarding each of the *Healthy People 2010* objectives. The group invited input from all key stakeholders. The Working Group ranked making progress on the research and evaluation objective as its top priority.

CDC's Office of Communication is encouraging systematic research and evaluation through four main strategies:

- Developing tools that facilitate research—(1) CDCynergy, a CD-ROM tool outlining the health communication planning, implementation, and evaluation process and (2) HealthComm KEY, an online database of health communication research
- Offering access to and expert consultation in marketing databases
- Offering access to and expert consultation in purchasing the services of research and evaluation contractors
- Developing a research agenda and supporting communication research that is consistent with the agenda.

Since 1994, the small business grant program for media technology health communication conducted by NCI has actively tracked grant research, evaluation, and outcomes. Grants and outcomes are synthesized; developed products are showcased to the National Institutes of Health (NIH) community; research and product information is made available to the public online; and NCI is currently having the Small Business Innovative Research (SBIR) products evaluated. This SBIR grant program is also currently building a repository of all evaluated media technology health communication grants and contracts within NIH.

The characteristics of all non-small business grants in NCI's Division of Cancer Control and Population Sciences are currently tracked through its Portfolio Management Analysis system. This means that all health communication research grants within the Division are monitored and evaluated. In addition, NCI has made a major commitment to research dissemination and diffusion through its Translating Research into Improved Outcomes program. In the Division of Cancer Control and Population Sciences, each program and branch has formed knowledge transfer teams that include scientists and health communication experts from NCI and, in some cases, from other parts of HHS. These teams are developing and acting upon strategic plans to close the gap between research discovery and program delivery.

FACTORS THAT CAN INFLUENCE CHANGE

Many challenges and issues arise in getting communication activities to include systematic research and evaluation.

- Securing approval and resources for research *and* evaluation of communication programs and significant communications components within larger interventions is a challenge. Many communication professionals advise that communication be better integrated with other program elements, yet the communication elements require their own analysis. How can communication research outcomes be "teased out" from endpoint or programmatic outcomes? (Many programs do not have explicitly stated logic models that guide evaluation activities of the overall program, let alone the communication components.)
- Working with many public health and healthcare professionals trained in medical model research in which the "gold standard" is the randomized control trial (RCT) can present difficulties. Communication activities have as their goal synergistic effects of messages from many messengers through many types of media. Health research has as its goal the controlling of as many confounders as possible to prove specific cause-and-effect relationships. Applying the RCT model to prove communication effects has been unproductive, especially when considering relatively small differences in exposure of messages between treatment and

control groups (Hornik, 2002; 1996). In fact, most resource gatekeepers expect robust data to support communication as an effective intervention, but they do not acknowledge the attributes of communication interventions that make them challenging to study. Hornik argues that for communication interventions to be effective, "the necessary level of exposure and extent of diffusion through a social system is such that it is impractical to maintain clear treatment and control conditions." Although the communication literature offers good data to support what communication can accomplish, it does not do so in the manner deemed robust enough for key gatekeepers. Hornik recommends a number of approaches (e.g., natural experiments, time-series designs, other quasi-experimental approaches). These approaches are often used in other research domains where it is unethical to have a true control group (e.g., welfare, social services, employment, criminal justice, education). What are the best models for showing the impact of communication interventions? How can these models be legitimized among resource gatekeepers who see the randomized control trial as the gold standard?

- It can be difficult to acquire resources to conduct robust process and summative evaluation. Much progress has been made in encouraging programs to conduct audience research in the formative phases of their program development. However, less progress has been made in developing affordable, timely, and doable evaluation of communication exposure, delivery, and effects. More important, the assumption is that more evaluation is better. But when resources are limited (as they always are) and decisions are made between providing a communication service or product and evaluating that service or product, production wins out over evaluation. What is the optimal resource allocation mix for developing, delivering, and evaluating health communication products or services? What data are available to support the optimal resource allocation mix for research and evaluation of health communication products or services?

- Policies and related systemic barriers faced by Federal agencies include difficulties in obtaining timely Office of Management and Budget (OMB) approvals for conducting audience research and surveys; lengthy clearance processes that effectively prevent audience research; limited support for funding optimal research and evaluation for communications programs; and the Government Performance Reporting Act's emphasis on the quantity, not quality, of Government activity.

- It is difficult to make generalizations about best practices for health communication that are not tied to specific disease topics or specific audiences. Research is typically topic or audience-specific and does not aim to make general conclusions about communication. Programs are built on logic models that try to get at contextual clues of the target behavior and the target audience, not generate general principles.
- There is an increasing demand for more accountability.
- There is growing sophistication in the field of health communication that is changing norms and expectations about what health communication can achieve.
- The demand for health information, especially online health information, is increasing (Boston Consulting Group, 2001; Fox et al., 2000). For example, a national survey of a representative sample of approximately 2,500 U.S. adults found that the percentage of respondents who said that they agreed or strongly agreed with the item, "I need to know about health issues so I can keep myself and my family healthy" increased from 66.9 percent in 1999 to 75.2 percent in 2000. In response to the statement, "It is important to me to be informed about health issues," affirmative responses increased from 66.8 to 69.2 percent. Both of these increases were statistically significant (Pollard, no date).
- The establishment of health communication objectives in the *Healthy People 2010* health objectives for the Nation was a critical first step in getting health communication on the public health agenda. Although the process for developing the 2010 health objectives for the Nation was clear (that is, there were publicly known mechanisms for providing input through the Web, in writing, and in public hearings), a similar process does not exist for discussing implementation

efforts on behalf of the objectives. Not having a known mechanism for interacting, discussing, or convening stakeholders beyond the development phase is a barrier to achieving the stated objectives. It is important for a mechanism to be identified and implemented so that health communication stays on the Nation's public health agenda.

STRATEGIES AND SOLUTIONS

- Develop and widely promote the use of recommendations on how to design appropriate communication-specific research and evaluation for interventions with significant communications components. (Develop industry minimum standards for communication program research and evaluation as well as criteria to assess when summative evaluation is absolutely needed.)
- Develop viable and credible evaluation models for communication and disseminate them through professional channels to communications and evaluation decisionmakers. Educate professionals about the value of health communication research and its contributions to understanding other phenomena. Explain why randomized control trials are not appropriate for communication research (e.g., no control of dose/exposure, confounders good).
- Develop evidence-based recommendations for allocating resources for use by communication professionals justifying program plans and resource requirements. Research the costs and return-on-investment for various communication approaches to provide guidance for decisionmakers.
- Explore the feasibility of an expedited review process (or exemption) from OMB clearance for Federal research and evaluation of health communication interventions.
- Develop criteria or a framework for culling out best practices in health communication that can be used across disease and audience contexts.

ACTION STEPS

Obtain stakeholder support endorsing more and better research and evaluation in health communication

interventions. This could be tied to the release of the *Healthy People 2010* Health Communication Action Plans.

Renew the commitment of academic institutions to train health communication professionals in research and evaluation. Institutions should train "generalist" health communication professionals (those who understand the basics of research and evaluation) and "specialist" health communication research and evaluation professionals (those who can conduct rigorous communication research) (Riegelman and Persily, 2001).

Promote discussions of revisions to OMB rules to faciliate the conduct of audience research (expedited procedure or exemption).

- Explore other ways to support communication research and evaluation, such as innovative collaborations with non-Federal entities.

Develop consensus on alternative models for evaluating communication effects that have credibility among health communication and key resource gatekeepers.

- Summarize evidence for determining best research designs for conducting communication research and evaluation.
- Publish and promote the integration of findings into practice.

Develop "model" language—for inclusion in Requests for Proposals (RFPs), Requests for Applications (RFAs), and program announcements—that supports health communication research and evaluation.

- Encourage the inclusion of health communication research and evaluation in Federal RFAs, RFPs, and program announcements.

Encourage Federal stakeholders (HHS) to collaborate on conducting a benchmarking study.

- Determine the extent to which HHS agencies are currently conducting or funding health communication research and evaluation.

- Identify policies and procedures that either help or hinder health communication research and evaluation.
- Offer recommendations for changing policies and procedures that will support achievement of this objective.

Explore the potential for HHS support to establish a Federal (Office of Personnel Management) professional job series to recognize health communication research and evaluation personnel.

Delineate competencies of health communication professionals.

Promote additional resources for health communication and health communication research and evaluation. Few Government health agencies have ever been given the resources needed to ensure exposure of health messages; they rely on public service advertising. Purchasing media time is one way to ensure exposure, which is a critical first step in evaluating the effectiveness of health communication interventions (Hornik, 2002; 1996). However, purchasing media time is costly.

Develop better methods for measurement in health communication research and evaluation.

- Develop measurement guidelines.
- Develop models for measuring communication effects at the group or community level (not just the individual level).

Offer recommendations for how to deal with issues arising from differentiating or integrating communication evaluation in overall program evaluation efforts.

- Offer recommendations for allocating resources for different types of evaluation.

Increase the number of health communication articles published in public health and medical journals.

- Educate editors and reviewers regarding appropriate models for evaluating the merits of health communication research. Note: Most best-practices documents use medical-model strength of evidence criteria that often disqualify health communication interventions.

Boston Consulting Group. *Vital signs update: the e-health patient paradox.* May 2001.

Fox S, Rainie L, et al. *The online health care revolution: how the Web helps Americans take better care of themselves.* The Pew Internet & American Life Project: Online Life Report, November 2000.

Freimuth V, Cole G, Kirby S. Issues in evaluating mass-media health communication campaigns. In: *Evaluation in health promotion: principles and perspectives*, I. Rootman et al., eds. Copenhagen: World Health Organization, 2001.

Hornik R. Introduction. In: *Public health communication*, R. Hornik, ed. Mahwah, NJ: Lawrence Erlbaum Associates, 2002.

Hornik R. Public health communication: making sense of contradictory evidence. Paper presented on October 31, 1996, at the Annenberg School for Communication, Philadelphia, PA.

Pollard W. Data from Porter Novelli's Healthstyles. No date.

Riegelman R, Persily NA. Health information systems and health communications: narrowband and broadband technologies as core public health competencies. *Am J Pub Health* 2001; 91(8):1179-83.

OBJECTIVE 11-4
DISCLOSURE OF INFORMATION TO ASSESS THE QUALITY OF HEALTH WEB SITES

DRAFTER

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TEXT OF OBJECTIVE

Increase the proportion of health-related World Wide Web sites that disclose information that can be used to assess the quality of the site.

SCOPE

The objective is intended to represent an important aspect of quality improvement for health Web sites but cannot encompass all issues raised by and related to the subject. The objective means to serve the specific purpose of providing data on progress for health Web site quality improvement and the general purpose of stimulating discussion about a wide range of health Web site quality issues.

MEASUREMENT

The objective is developmental. Several elements are needed to make this a measurable objective. These elements include a reliable estimate of the number of health-related Web sites and the number of health-related Web sites that disclose information that can be used to assess quality; consensus about which information should be disclosed to assess quality; and an organization or governmental entity to undertake assessment and measurement. It may be possible to work with Internet search engines and directories to develop a methodology to create a proxy number for the total number of health-related Web sites.

The explicit purpose of the objective is to ensure that Web sites properly disclose certain information about their operations. The supporting text for the objective identifies six types of information that should be disclosed to users of health Web sites.

- Identity of the developers and sponsors of the site (and how to contact them) and information about any potential conflicts of interest or biases (Note: "Bias" is not intended to mean simply a point of view or perspective but a systematic prejudice or predisposition that is intended to influence a user unfairly.)
- Explicit purpose of the site, including any commercial purposes and advertising
- Original sources of content on the site
- How the privacy and confidentiality of any personal information collected from users is protected
- How the site is evaluated (in terms of impact on users as a result of interacting with a Web site's functions)
- How the content is updated

Although not a matter of information disclosure, Web sites should also be accessible to all users, including those with disabilities and low-end technology.

ISSUES PERTAINING TO MEASUREMENT

The inclusion of this objective in the Nation's public health agenda represents the belief that the implementation and measurement of the diffusion of disclosure and quality standards for health Web sites is vital, not only to improve individual Web sites, but also for the credibility of the e-health field as a whole and the overall improvement of the public's health. The challenges to achieve improvements should not be underestimated, although numerous groups have made substantial progress to identify ethical practices, disclosure mechanisms, and quality standards for health Web sites.

Defining the universe of health-related Web sites is difficult. An infinite and ever-expanding number of Web sites offers an ever-increasing variety of functions. Some Web sites are clearly providers of mainstream health information and services; others mix health with other subject areas, leaving the boundaries on "health" information unclear. For example, should all lifestyle information be considered "health-related"? How should the categories of "alternative and complementary medicine" be treated? Should personal Web sites or even pages posted by an individual to express a point of view or personal experience with a health issue be considered health-related Web sites? If the most expansive definition of "health-related" is used, even more Web sites may need to be considered, and it is not yet clear how this term should be applied in either the short term or the long term.

The objective is based on the principle that public disclosure of critical information about Web site operations will benefit users. Disclosure is considered an essential first step in the process of quality improvement. However, disclosure alone is unlikely to accomplish the larger goal of the objective, which is to improve the quality of health Web sites, not just increase the amount of information disclosure. In lieu of an oversight and enforcement mechanism for Web site quality standards, disclosure is used as a proxy for quality, not quality itself. Quality is constituted by the actual characteristics of a Web site, its practices and policies, and the value of the site and its content to users. Moreover, disclosure doesn't necessarily change consumer behavior to seek out the highest quality Web sites, although disclosure may make the behavior more likely. One of the limitations of a disclosure approach for Web sites is that, to date, it has been a purely voluntary effort, and it is not clear how broad and deep the support among Web site sponsors is for disclosure. Also, little effort has been made to make information about Web sites easily understandable for consumers.

An issue that underlies disclosure is the difficulty associated with developing and implementing Web site quality standards. Elaborating, operationalizing, and maintaining core elements and definitions of quality standards require considerable work. Once the standards are developed, they need to be implemented consistently, presented understandably, and disclosed publicly. Mechanisms to monitor their use and enforce their proper application do not yet exist and will require a substantial commitment of resources and effort. An additional issue is the applicability of standards, particularly voluntary ones, across the spectrum of Web sites. Government Web sites, for example, may have specific obligations or standards based on legal or regulatory requirements or the mandate of the agency or office that sponsors the Web site. Private-sector Web sites that engage in a specifically regulated activity, such as the sale of prescription medication, may be subject to their own sets of criteria. It is not clear how many different sets of standards can be meaningfully applied to a given Web site or a set of content, or if a single set of criteria could be meaningfully applied to all health Web sites.

The proliferation of Web site standards may present another problem for creating an environment for meaningful disclosure. Inundating users with information about every aspect of a Web site's operations will likely create a situation of information overload, resulting in user frustration and lack of interest or time to process all the different approaches and pieces of information. Standard criteria and templates, whether in human or machine-readable languages, have been proposed as a solution by some organizations. Web site sponsors, search engines, and directories may be reluctant to agree on standards, however, if they perceive that their own ability to respond to market conditions and their user base will be limited as a result.

STATE OF KNOWLEDGE ABOUT ISSUES REPRESENTED BY THE OBJECTIVE

The objective intends to promote greater disclosure of information about health Web site content and operations so that users can determine for themselves the degree of quality and appropriateness of the site and its content or features. A disclosure approach is not intended to assess whether Web site content is accurate. Rather, disclosure of key information allows potential users to compare Web sites and decide which they can trust and which are the most suitable for their needs. Disclosure of key information has been used in situations where users may have differing perceptions of what constitutes "appropriate" and "high quality." In the context of Web sites, "quality" is not limited to the caliber of information on the site; it extends to multiple elements that bear on reliability, value, and user protections.

The idea of disclosure of information about Web site operations as a means to assess appropriateness and quality borrows from other consumer sectors and health interventions. The assumption is that consumers—whether of manufactured products, medical procedures, or Web sites—need information to make the most informed decisions. Examples include the practice of giving patients information about the risks and benefits of medical treatments or experiments or giving potential purchasers information about consumer products or services. The nutritional food label is one of the most well-known implementations of the disclosure approach. The label is required to appear on most types of packaged and prepared foods and to provide specific information about the nutritional characteristics of food items so that consumers can decide for themselves if the food fits their own dietary needs. The label and its constituent elements have been subject to extensive public comment and are standardized. The Food and Drug Administration, the Federal agency with oversight responsibility of the food label, has put a great deal of effort into research and evaluation of consumers' understanding and use of the label to make the label "consumer-friendly." Research has shown that consumers do use information from food labels to make purchase choices and that those who do can positively influence their nutritional intake.

In the Internet context, much of the debate about disclosure of information has occurred in relation to Web sites' handling of users' personal information. Congressional committees have held numerous hearings to discuss the information practices of Web sites. The Federal Trade Commission (FTC) and numerous research organizations and advocacy groups have conducted studies and issued reports documenting that in general Web site users are ill-informed about Web sites' information practices. Even savvy Web users often have a difficult time understanding the privacy policies that Web sites post to disclose their information practices. The FTC has proposed that Web sites adopt fair information practices to inform consumers of the uses of their personal information. Notably, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which is the latest set of Federal regulations on health information privacy, will not affect most health Web site operations. Technology tools, such as the Platform for Privacy Preferences Project (P3P) standard for matching users' preferences with the elements of Web sites' privacy policies, are also emerging and contributing to the advancement of a disclosure approach. However, credible research is lacking on the impact of making users more aware of privacy and disclosing specific practices (e.g., disclosure, fair information practices, P3P).

Although not specific to Web-based information or the health sector, information quality standards will achieve a new level of rigor and prominence with the implementation of Federal "Guidelines for Ensuring and Maximizing the Quality, Objectivity, Utility, and Integrity of Information Disseminated by Federal Agencies" (Section 515, Public Law 106-554; H.R. 5658). As of October 1, 2002, all Federal agencies are obligated to develop and abide by information quality standards that will apply to almost all information disseminated to the public, including Web-based health information. The guidelines are likely to have an impact on information practices beyond the Federal Government. Federal agencies will need to review not only the information they create but also third-party information that agencies disseminate as their own. Non-Federal and private-sector organizations that supply information to Federal agencies may need to change their own information practices to meet agency standards. In this way, the standards may shift expectations and practices across all sectors, including health information.

STAKEHOLDERS

The ultimate goal of the objective is to increase the proportion of reliable health Web sites. Those who would benefit from this are numerous and varied. However, some Web site sponsors benefit from the continued dissemination of misleading or false information because it helps to sell their products, however ineffectual or dangerous. Although these types of Web sites can never be completely eliminated, their visibility may be diminished if the proportion of reliable Web sites increases.

The following list includes any group that has a reasonably substantial interest in the disclosure of information about health Web sites.

- Web site sponsors
- Health information seekers (consumers, patients, families, and caregivers)
- Healthcare professionals and their professional societies
- Healthcare provider organizations (private and public)
- Health insurance providers
- Managed care organizations
- Public health organizations
- Third-party reviewers and accrediting bodies
- Government—regulators, information providers, protectors of the public interest, consumer protection groups, healthcare providers, and researchers
- Search engines
- Foundations
- Academic and research institutions
- Media watchdogs
- Consumer advocates
- Mass media
- Libraries
- Health info-mediaries—organizations that help their constituencies access and use health information
- Health educators

- Literacy and health literacy experts
- Trade associations
- Health industry groups—pharmaceuticals and medical products and devices
- Technical community
- Sellers of health information—online and offline bookstores (e.g., Amazon, Barnes & Noble)
- Net advisory services

Some groups will be more interested and motivated than others. Web site sponsors want to be perceived as credible and reliable providers of information and services and need mechanisms to signal their credibility and reliability to consumers. Internet search engines enhance their own popularity, credibility, and economic viability when they direct searchers to the information they need in the most efficient, reliable manner, which may be easier to do with disclosure and quality criteria. Health information seekers need credible and reliable information to make informed decisions and high-quality services to realize the maximum improvements in their health, and disclosure and quality criteria may be important tools to help them. Healthcare professionals are also information seekers, as well as sources for referrals, and they need quality information so that they know they can rely on the Web sites they use and to which they refer their patients. Health services and insurance providers need their own Web sites to be perceived as credible, and they need to know that the patients they treat and insure are using reliable information to make decisions that affect their health. In addition to their functions as health insurers and service providers, governments are responsible for providing health information in a reliable manner, protecting consumers from harm, and promoting the public interest in having a safe Web environment and reliable health information and services.

STATUS OF SELECTED STAKEHOLDER ACTIVITIES

Various mechanisms have been proposed to help users assess Web site quality, which include mechanisms to protect users' privacy. All mechanisms rely at least in part on Web sites' disclosure of information about their operations. Without disclosure, it would be virtually impossible to answer most of the questions on the quality checklists, seal assessment forms, and other tools, or to check for compliance with quality standards that have been developed by the initiatives described below. Numerous groups have created checklists that consumers can use to assess Web sites. Seal programs, such as the HON code and TRUSTe, provide minimum criteria that Web sites must meet to receive the right to display the seal.

Some e-health companies collaborated to draft a code of ethics for health Web sites (Hi-Ethics). The Internet Healthcare Coalition (IHC) convened a diverse group of interested parties, including some Hi-Ethics members, to draft a separate code of ethics. URAC, an accrediting body for healthcare organizations, has created a program to allow health Web sites to apply for accreditation. The URAC standards encompass elements of the Hi-Ethics and IHC codes. Professional societies have created their own referral programs and networks to direct consumers to reputable organizations and Web sites. The American Medical Association (AMA) has created quality guidelines that it uses to govern operations on AMA-affiliated Web sites.

Government agencies have created portals and Web sites to distribute reliable information and links to other organizations and sources of information. The World Health Organization proposes to create and manage a dot-health domain name that would function as a label for trustworthy health information. The European Union funded an initiative called MedCERTAIN, envisioned as a self- and third-party rating system with metadata tagging technology, standard quality vocabulary, and content filtering labels. MedCIRCLE, a new initiative, expands on MedCERTAIN and aims to realize the application of standard vocabularies and the interoperability of rating services and gateways.

The U.S. Department of Health and Human Services (HHS) is implementing several ongoing activities. In response to the Federal law on "Guidelines for Ensuring and Maximizing the Quality, Utility, and Integrity of Information Disseminated by

Federal Agencies," HHS has drafted departmental and agency-specific guidelines on information quality. HHS also has draft guidance on developing agency policies about linking to Web sites external to the Department. The Multimedia Technology Health Communication small business grant program at the National Cancer Institute (NCI) has funded two projects to develop Web assessment tools. NCI staff has developed a tracking model for grantees and contractors that includes consistent procedures for usability testing and for assessing the quality of site content.

FACTORS THAT CAN INFLUENCE CHANGE

The Internet is a very fluid environment, and the factors that can influence the disclosure of information about Web sites and their content and the diffusion of quality standards can emerge and recede quickly. The following list identifies the most likely reasons that Web sites may begin to disclose information, the likely leverage points to encourage disclosure, or potential barriers that could impede disclosure or make disclosure less effective. Some of these factors may be specific to health Web sites, although many reflect the broader Internet environment and public perceptions of the Web and Web site practices.

Pending or actual legislation

- *Self-regulation.* Web site sponsors and their business partners have been concerned about the potential for regulation of Web site operations, specifically regulation of the use of consumers' personal information. The industry has responded by launching numerous self-regulatory efforts and testifying frequently to Congress about the viability of self-regulatory mechanisms. More robust disclosure could be an important element in convincing legislators that Web sites are providing enough information to consumers to make self-regulation workable.
- *Legislation in other sectors.* The notices mandated by the Gramm-Leach-Bliley Act (GLB) have brought attention to the process of disclosing information to consumers. Under GLB, financial institutions are required to provide notices to

their customers about their information-collection and information-sharing practices. The financial services sector has been publicly criticized for the quality of these notices. The FTC held a workshop in December 2001 for companies to learn more about disclosure and providing notices about privacy for consumers. Privacy regulations under HIPAA will also be a high-profile test of how to give consumers notice about information-handling practices. In addition to increasing the amount of notice in the financial services and healthcare sectors, GLB and HIPAA may become important models of how to disclose information about many types of business practices, including Web site operations.

Marketplace considerations

- *Failure of dot-coms.* As a result of difficult market conditions, Web site sponsors may be more interested in finding ways to retain customers and develop long-term relationships with them. Companies may perceive disclosing information about their Web operations as one way to enhance their reputations and attract and retain customers.
- *Image and public relations.* The ability to enhance Web sites' reputations through positive publicity, or fear of potential damage to image from adverse publicity, may motivate information providers to adopt disclosure mechanisms and quality standards.
- *Transparency.* Disclosing practices that Web site sponsors may be uncomfortable defending in public may motivate them to change and improve their practices.
- *Burden of disclosure.* Web site sponsors may view the perceived financial and administrative burdens of reporting information and redesigning Web sites to make information easy to find and use as a barrier to disclosure of information.
- *Financial costs of disclosure.* Disclosure may impose financial costs on Web sites for several reasons. Web sites may need to be redesigned to accommodate the disclosure of information about quality criteria. Web site sponsors that decide to seek accreditation through URAC or other means have to pay a fee to the accrediting body as well as cover the costs

associated with staff time to prepare for the review and to redesign business functions to meet standards.

Government Web sites

- *Applicability of disclosure and standards to Government Web sites.* Government Web sites may be reluctant to participate in disclosure and quality standard mechanisms that either are designed to fit the operations of non-Government Web site operations or require submitting the site to marketplace considerations, such as paying for accreditation or being listed in a directory or search engine. Several outcomes are possible if Government Web sites decide not to use the same quality standards and disclosure mechanisms as those used by non-Government Web sites. Non-Government Web sites may decide that disclosure and quality criteria cannot be that important if Government Web sites are not willing to use them. An artificial distinction could be made between Government Web sites and non-Government Web sites because Government information is available on many different types of Web sites, some of which are clearly dot-gov and some of which aren't, including those that are clearly commercial.

Media activities

- *Media activism.* The media have reported numerous electronic mishaps related to the unauthorized release of identifiable personal information. Mistaken e-mails, files that should have been erased but were left on computers, and unauthorized sharing of personally identifiable health information are a few examples that have appeared in the headlines. In national surveys, consumers repeatedly report concern about how much information is collected about them while they are on the Internet and who has access to that information. Public comment about the recently enacted privacy regulations for healthcare transactions also indicates concern by consumers about the electronic information flow among organizations that provide health care. If media coverage feeds public fears about abuses, disclosure may be seen as insufficient to deal with the magnitude of the problem.

- *Media framing of quality issues.* Consistent use of media for advocacy of quality standards could enhance the media's watchdog role and promote consumer awareness regarding Web content. Responsible (instead of inflammatory) stories on fraudulent and unethical practices could promote outrage and action on the part of consumers, rather than broadly dampen enthusiasm for using the Web as a health resource.

Attention on quality

- *Break-out of one (or more) of the quality initiatives.* If some of the most popular health Web sites begin to use one of the more robust approaches described above and they receive large amounts of favorable publicity, public demand for disclosure of information and adoption of quality standards may increase.

- *Best practices.* The development of best practices for disclosure and quality standards could reinforce the behavior of those Web sites that are implementing the practices and be a prod for those sites that aren't.

- *Healthcare providers' adoption of Web tools.* Healthcare providers could take on more of an opinion leader role in recommending the best Web resources. This would help dilute the typically negative opinions that many healthcare providers express about resources for consumer health information and provide an important conduit for awareness and education activities with patients.

- *Emergence of a market leader for Web site seals and recommendations.* Seals and recommendations are based on the ability to assess Web sites' activities. If a small number of seals and related identifying marks or logos emerge as credible and meaningful to consumers, disclosure would consequently be enhanced.

- *Visible support.* Employers, other sponsors of health insurance, and information intermediaries could insist that their agents—such as health plans, employee assistance programs, and disease management programs—use only health information services that disclose information about their Web site operations and meet quality standards.

Technical factors

- *Emergence of technical solutions.* Standards, such as P3P, and one-click access to an "About Us" section that relays core information to users could make it easier for Web site sponsors to engage in disclosure.
- *Filtering software.* The proliferation of tools to recommend sites could direct users to sites that disclose meaningful information in an easy to understand way and direct users away from sites that don't.

User considerations

- *Information overload.* In the interest of full disclosure or perceived liability considerations, Web sites may provide so much information about themselves and their operations that users become overwhelmed by the amount of information that they need to assess the quality of a Web site. Or, because of the lack of standardization in disclosure, users may find they need to learn multiple approaches to seek out information on Web pages as they move among sites, which could also create information overload. The likely consequences are frustration and an eventual lack of interest or at least attention to the information provided.
- *Disparities.* The success of disclosure as a tool to help consumers will be influenced by the characteristics of Web site users. Users differ greatly in their health status, their fluency in the language used to present information, and their skills in information processing, general literacy, technology literacy, and health literacy. Also, the sophistication of the information presented on Web sites, in terms of both health content and information about Web site operations, tends to be very high, which would make the site difficult to use for a large number of health information seekers.

STRATEGIES AND SOLUTIONS

Premise: Promoters of disclosure and quality standards need to find solutions that put the least amount of burden on users. Three general strategies have been identified.

Create market advantage for quality (of interest to search engines, directories, other aggregators of Web content, and evaluators of Web sites and their content).

- Encourage dissemination of information about trusted sites.
- Promote, publicize, and reward good information practices; recognize the best and the worst.
- Promote editorial "brands" for the most reputable sites.

Build demand for quality.

- Encourage public education to alert Web site users to disclosure, quality criteria and standards, how to identify them, and how to interpret seal programs or other disclosure mechanisms.
- Make communicating with Web site users about quality a priority.
- Engage health info-mediaries: they are the conduits to particular user groups and audiences to discuss quality and how to use the Web.
- Engage in counteradvertising: Web advertising could be used to direct users away from unreliable and low-quality sites and toward reliable and high-quality sites. One method might be ads that remind users of corporate and other influences on site content.

Build capacity to use quality criteria.

- Rewrite Web site policies in a simple and focused manner to convey only the most relevant information to consumers.
- Develop a template to allow users to identify the information being disclosed easily and quickly.
- Develop users' critical information-seeking skills.
- Collaborate with K-12 educators to integrate health content into school-based programs that teach technical skills.
- Educate Web publishers about the importance of incorporating quality criteria.

ACTION STEPS

This section identifies the necessary steps for measuring the objective or supporting the three strategies outlined above. They are not in sequential order. Many of these actions could occur simultaneously and in coordination with each other.

- Define and characterize major categories of health-related sites for identification and quantification.
- Identify core elements and definitions of quality standards.
- Conduct consumer testing to find out what consumers understand about disclosure and quality standards on health Web sites.
- Create a communication tool (e.g., label) to help Web site users understand the information disclosed about Web site operations.
- Explore U.S. Department of Education programs for teaching "skills for the digital age" to see if health content can be included.
- Mobilize health info-mediaries to help stimulate consumer demand for disclosure and quality.
- Engage groups involved in health literacy in skill building around the use of Web resources.
- Identify potential template approaches (e.g., P3P, the food label).
- Identify industry leaders in quality improvement for Web sites.
- Create a mechanism to monitor adherence to quality standards.
- Develop self-applied tools for Web publishers to enhance their understanding of quality issues.
- Research the operations and practices of Internet search engines and directories to understand their methodologies and market influences.

- Open discussions with search engines about the possibility of incorporating quality criteria and disclosure templates in the search and directory processes.
- Identify ways to publicize search engines and directories that steer users to more reputable sites.

FOR MORE INFORMATION

American Medical Association
www.ama-assn.org/ama/pub/category/1905.html

Hi-Ethics
www.hiethics.com

Health on the Net
www.hon.ch

Internet Healthcare Coalition
www.ihealthcoalition.org

MedCERTAIN
www.medcertain.com/english/metadata/overview.htm

MedCIRCLE
www.medcircle.org

URAC
http://webapps.urac.org/websiteaccreditation/default.htm

Baur C, Deering MJ. Proposed frameworks to improve the quality of health Web sites: review. *Med Gen Med.* September 26, 2000:E35. Available online at www.medscape.com/Medscape/GeneralMedicine/journal/2000/v02.n05/mgm0926.baur/mgm0926.baur-01.html.

Baur C, Deering MJ. Commentary on the "Review of Internet health information quality." *J Med Internet Res* 2001;3(4). Available online at www.jmir.org/2001/4/e29/index.htm.

Eysenbach G. An ontology of quality initiatives and a model for decentralized, collaborative quality management on the (semantic) World Wide Web. *J Med Internet Res* 2001;3(4). Available online at www.jmir.org/2001/4/e34/index.htm.

Mack J, ed. *The new frontier: exploring ehealth ethics.* Washington, DC: URAC/Internet Healthcare Coalition, 2001.

Risk A, Dzenowagis J. Review of Internet health information quality. *J Med Internet Res* 2001;3(4). Available online at www.jmir.org/2001/4/e28/index.htm.

OBJECTIVE 11-5
CENTERS FOR EXCELLENCE IN HEALTH COMMUNICATION

DRAFTERS

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TEXT OF OBJECTIVE

Increase the number of centers for excellence that seek to advance the research and practice of health communication.

SCOPE

The objective is intended to represent an important aspect of the research and practice needs of the health communication field but cannot encompass all issues raised by and related to the subject. The objective means to serve the specific purpose of providing data on progress to establish centers for excellence and the general purpose of stimulating discussion about a wide range of research and practice needs in the health communication field.

MEASUREMENT

The objective is developmental. The health communication chapter in *Healthy People 2010* (U.S. Department of Health and Human Services [HHS], 2000) notes that

> To enlarge the knowledge base of health communication and incorporate it into health promotion practice, a research and training infrastructure is needed to develop, model, and coordinate activities. For this purpose, centers for excellence located in academic institutions, national organizations, or research centers would be instrumental to meet scientific and practical needs.

Several elements needed to make this a measurable objective are currently being defined. These elements include consensus about the center concept and necessary criteria to identify centers for excellence. At present, several self-identified programs around the Nation are conducting research involving health or public health and communication. Most of these are engaged in "applied" research, using existing health communication knowledge and techniques to solve particular health problems, versus focusing on "basic" research involving the processes or mechanisms of health communication research per se.

The National Cancer Institute (NCI) has taken the lead to create and fund a network of centers to accelerate the research and development of interventions for cancer communications. The grant program will fund multiple Centers of Excellence in Cancer Communications (CECCRs). The centers will encourage focused interdisciplinary studies to accelerate scientific developments in cancer communications, increase the number of investigators from a range of disciplines who focus on the study of cancer communications, and train investigators to conduct cutting-edge communications research. Because of NCI's central role in the development of formally designated centers, the Institute has been identified as the entity to undertake regular assessment of the objective.

1. Because excellent health communication research may take place in a variety of contexts (e.g., research centers, university departments, corporate units), criteria are needed to characterize "centers for excellence." These criteria could be used to identify existing centers or to promote the development of future centers. Criteria might include

- A primary focus on health communication research
- A critical mass of researchers doing health communication research on a continuing basis
- An operational emphasis on interdisciplinary research teams to provide both breadth and depth in theory and methodology
- A clear, efficient, and effective administrative structure to manage the financial, operational, and personnel needs of the research unit
- Solid institutional support to provide a stable research environment
- Ongoing activities such as
    - A well-defined health communication research program
    - Frequent publication of the unit's research in book or journal form
    - The acquisition of significant levels of research funding
    - Mentoring programs to involve students (graduate or undergraduate) in research projects as a means to train future health communication researchers
    - Postdoctoral training opportunities
    - Clearly defined marketing, recruiting, and networking mechanisms
    - Publications detailing the center's characteristics, structure, and activities.

2. Information is needed to profile and track ongoing health communication research taking place around the Nation. This would best be accomplished through a longitudinal survey mechanism to

- Identify existing centers and research programs as a benchmark to document who is doing what kinds of research in which locations.

- Provide a context for conceptualizing activity in the field. Having a comprehensive picture of the research activities taking place would be an important aid to conceptualizing and defining the field.
- Identify areas of needed research. Through knowledge of the ongoing activities of the field, it would be possible to document the gaps in knowledge and research methods.
- Monitor and track research activities and accomplishments across time. After the initial benchmark profiles of research activity are established, periodic surveys should be done to update the database, track long-term projects, and document the evolution of the field.
- Provide empirical justification for future centers for excellence initiatives. Having an ongoing profile of health communication research activities would provide a wealth of information to justify recommendations for future centers.

3. This action plan provides an initial assessment of relevant stakeholders. A more thorough assessment is still needed to determine who the stakeholders are, their levels of activity and involvement, their needs, and the resources they could bring to the creation of centers for excellence. Having this information would make it possible to better organize and coordinate the diverse activities of the stakeholders toward the common goal of establishing and maintaining centers for excellence. For example, it may also be important to consider building capacity for the application of communication strategies, tools, and theories in programs that prepare professionals or develop programs to reach the most underserved communities. Thus, investing in community-based participatory research partnerships between centers for excellence in health communication, Minority Serving Institutions (e.g., Historically Black Colleges and Universities), and national minority-focused leadership organizations (e.g., National Association for the Advancement of Colored People and National Council of La Raza) may be critical to ensure that the populations that bear the greatest burden of disease benefit most from new health communication approaches identified through research.

ISSUES PERTAINING TO MEASUREMENT

Assessment issues are linked to the functions of the centers for excellence. The health communication chapter of *Healthy People 2010* (HHS, 2000) describes these functions as follows:

- The centers would be responsible for an array of activities, such as (1) promoting the adoption of health communication theories and practices in health care, disease prevention, and health promotion initiatives; (2) developing and disseminating quality standards; (3) coordinating initiatives to develop a consensus research agenda; (4) developing systems to identify and assess health communication research; (5) evaluating communication strategies, messages, materials, and resources; (6) fostering networking and collaboration among health communicators, health educators, and other health professionals; (7) promoting health communication skills training for health professionals; and (8) promoting research and dissemination activities among specific population groups.
- These centers should provide expert staff, model curricula with core competencies in health communication and media technologies, appropriately equipped media labs, research seminars, continuing education and distance learning courses, and training and placement programs to expand the pool of health communication professionals and health professionals with communication skills. The centers also could create databases that would catalog items such as formative and outcomes research studies and reports and could partner with existing governmental dissemination networks to make data publicly available.

STATE OF KNOWLEDGE ABOUT ISSUES REPRESENTED BY THE OBJECTIVE

As the communications revolution blossoms, the amount and diversity of health information increases exponentially and, with it, the need for more effective ways to gather, store, and use the information. At no time in our history has the need to understand and effectively use health communication been greater. Communication is central to all forms of health care, from primary prevention to end-of-life issues. *Healthy People 2010* defines health communication as "the research-based crafting and delivery of messages and strategies to promote the health of individuals and communities." Health communication, when effectively used, can inform, educate, motivate, and empower individuals, communities, and nations.

For more than 50 years, social scientists from a variety of disciplines have been studying how humans interact in an attempt to develop predictive theories. In the health arena, these theories have increasingly focused on how people process health information and how they perceive and respond to health risks. In recent years, health communication theories have aided in the development of effective health campaigns addressing a range of topics, from smoking and drug abuse to nutritional awareness and personal fitness. In general, however, knowledge of communication processes and principles has not kept pace with the increasing complexity of health information environments (e.g., new media and Internet sources) and personal health challenges (e.g., new epidemics and threats of bioterrorism). As such, there is an exceptional need to develop programs and mechanisms to stimulate more health communication research, coordinate available research resources, train more qualified researchers, organize the growing body of knowledge, and disseminate this knowledge to scientists, health practitioners, patients, and the public. The 2010 objective to increase the number of centers for excellence in health communication research is an attempt to address this critical need for quality health communication information.

Overall, the science must be developed to the point where people can be taught to evaluate health risks, deal critically with conflicting health information, and make informed choices, including judgments about complementary and alternative therapies. We must learn how to effectively inform healthcare professionals of best practices on the one hand and how to better communicate with their patients on the other. We must also learn how to use our communication knowledge to reduce health disparities, while more effectively interacting with children, older persons, minorities, culturally disparate groups, and high-risk populations. Communication is an integral component in all healthcare contexts. By increasing the number of centers for excellence in health communication research, we will be better able to empirically apply our knowledge in ways that will increase both the quality of health care in America and the overall quality of life.

STAKEHOLDERS

The primary stakeholders for this objective are those organizations that are (or could be) directly involved in the development of centers for excellence initiatives and programs, such as

- Academic institutions with health communication research programs or interests
- Special interest groups involving patients, practitioners, or the public
- Industries with health foci that would benefit from improved health communications
- Governments at all levels and their research funding agencies
- International groups with health foci and missions
- Nongovernmental agencies with health-related missions
- Professional associations involving healthcare providers
- Patient advocacy groups
- Healthcare practitioners from a wide range of professions

Specific professional associations that focus on health communication research, education, and applications include

- International Communication Association
- National Communication Association
- American Public Health Association
- Western States Communication Association
- Eastern Communication Association

- Central States Communication Association
- American Telemedicine Association
- American Society for Preventive Oncology
- Society for Behavioral Medicine
- Society for Public Health Education

STATUS OF SELECTED STAKEHOLDER ACTIVITIES

The research program most closely related to the centers for excellence objective is the NCI research initiative to develop CECCRs. This interdisciplinary research initiative, the centerpiece of NCI's Extraordinary Opportunity in Cancer Communications, is a multiyear commitment by NCI to provide support for new research and outreach efforts in cancer communications. The novelty and scope of this initiative reflect the belief that effective communications can and should be used to narrow the enormous gap between research discoveries and applications and to help reduce health disparities. Communication is central to quality health care, from primary prevention to survivorship (Institute of Medicine, 1999). In June 2003, NCI awarded $10 million each to four research centers in support of the CECCR initiative.

The Request for Applications (RFA) mandated that CECCR applicants develop an interdisciplinary research team to conduct an innovative 5-year program of health communication research. These research programs should include three or more major individual hypothesis-driven, yet interrelated cancer communication research projects; plans for several emergent pilot or developmental research projects; strategies for shared resources; and plans for training and career development programs to prepare the next generation of cancer communications scientists. The RFA suggested that to be effective, the centers' research programs should integrate cancer communications appropriately into one or more contexts of the cancer continuum—from prevention through treatment to survivorship and end-of-life research. It encouraged the development of communications research studies about challenging topics such as cancer information-seeking, decisionmaking under uncertainty, and genetic testing. The RFA also encouraged development of research projects that would provide insights into mechanisms underlying how people process information. The centers' interdisciplinary efforts are expected to result in new or improved syntheses, theories, methods, and interventions, including those for diverse populations. The centers are expected to provide an essential infrastructure to facilitate rapid advances in knowledge about cancer communications, translate theory and programs into practice, and train health communication scientists.

CECCRs are expected to conduct research that will lead to major scientific advances in knowledge about cancer communications and their translation into practice. Several overarching goals include

- Increase the number of investigators from relevant disciplines who focus on the study of cancer communications as part of interdisciplinary teams.
- Increase the number of peer-reviewed publications in the area of communication processes.
- Generate basic research evidence to improve understanding of the processes underlying effective cancer communication.
- Produce evidence-based communication interventions that can be used to modify cancer risk behaviors and improve informed decisionmaking and quality of life.
- Support novel interdisciplinary research to inform medical, dental, pharmacy, and public health practitioners about how best to communicate to the public, patients, and cancer survivors.
- Increase the number of evidence-based interventions in understudied areas (e.g., diagnosis, treatment, survivorship, end-of-life) and on understudied populations.
- Train interdisciplinary investigators capable of conducting cutting-edge communications research directly relevant to the context of cancer prevention, detection, treatment, control, or survivorship.

The focus of CECCR research programs can include, but is not limited to, cancer risk communication, evidence-based interventions to enhance cancer communication, communication methods for diverse and underserved populations, innovative communication strategies to increase informed decisionmaking and participation in clinical trials, communication about genetic testing, survivorship and end-of-life issues, as well as communication interventions to improve cancer prevention and early detection behaviors. The CECCR RFA also invited research to elucidate the psychological mechanisms underlying the cancer communication process, to understand how people use cancer information, to test innovative strategies to overcome the digital divide in access to cancer-related information, and to develop and evaluate methods to enhance the dissemination of evidence-based cancer communication interventions. Researchers were encouraged to examine the ethical issues associated with cancer communications as well as the cost-effectiveness of evidence-based interventions. Messages and the way messages and information are developed, designed, displayed, and communicated should be based on scientific evidence. Yet, little research has been conducted on the usability of available cancer communications. Centers were encouraged to conduct basic, intervention, and diffusion research in a variety of settings, including laboratories and clinical and community settings. Programs should focus on translatability—from basic to intervention research to dissemination and sometimes back again.

The announcement of the CECCR initiative has focused considerable attention on health communication research. Top researchers from a number of different scientific disciplines—such as medicine, public health, communication, information science, psychology, sociology, anthropology, engineering, and gerontology—have begun new collaborations on health communication research projects. As a result of this initiative, health communication researchers are working with major cancer research centers, NCI's Cancer Information Service, healthcare delivery systems, managed care programs, social service agencies, and other Government-sponsored and nonprofit health organizations. Once the four new centers begin their work, an inevitable surge of innovative new programmatic and interdisciplinary health communication research activities will lead to new health communication research models, theories, methods, and applications. These activities will directly support the goals of this *Healthy People 2010* objective.

Important new health communication research centers also have been developed, or are currently under development, at a number of U.S. universities, such as the University of Kentucky, Northwestern University, University of Michigan, Johns Hopkins University, University of Southern California, Harvard University, University of Pennsylvania, St. Louis University, Texas A&M University, Duke University, University of North Carolina, Pennsylvania State University, Temple University, Case Western Reserve University, University of Missouri, and West Virginia University. Several major cancer centers, such as the M.D. Anderson Cancer Research Center, the Fox Chase Cancer Center, and the Fred Hutchinson Cancer Research Center, also are developing health communication research programs. These developmental activities also support the *Healthy People 2010* Health Communication Centers for Excellence objective. Furthermore, interest in research and educational activities concerning health communication is increasing among professional societies, private foundations, and other funding agencies.

FACTORS THAT CAN INFLUENCE CHANGE

Many major factors, listed below, could influence the development of centers for excellence.

- More funding targeted for the establishment of centers
- Agencies and institutions committing to the development of centers by including a center-like focus in mission statements and establishing research programs promoting health communication research
- Professional associations developing task forces to study and promote centers, priority statements, and action plans emphasizing centers, programs leading to the establishment of centers, and structures to evolve internal or collaborative centers

- Promotion of an information environment that would encourage center formation through information technologies and health information sources
- Encouragement for healthcare payors to develop centers related to prevention and focusing on health policy
- Support for health policies that encourage center development
- Refinement of diffusion mechanisms for promoting centers.

Successes associated with the NCI-funded CECCR program could encourage other researchers to engage in programmatic health communication research and outreach activities and could encourage new health communication funding initiatives by other Federal agencies, private foundations, and professional societies. However, any problems experienced by the CECCR program could discourage similar investments in health communication research and outreach activities. In addition, further downturns in the economy could discourage other large-scale initiatives in health communication centers for excellence.

STRATEGIES AND SOLUTIONS

Listed below are possible strategies for promoting the development of centers for excellence. The strategies are categorized, and each item is designated as either a long-term or short-term strategy.

Collaboration and Promotion of Centers

- Convene stakeholders to develop strategies for developing more centers. (short-term strategy)
- Promote centers within and across professional associations, at conferences, and at various types of professional meetings. (short-term strategy)
- Promote collaboration among professional associations for joint efforts to create and support health communication research centers. (short-term strategy)
- Encourage interagency collaboration to fund centers. (long-term strategy)

- Encourage increased funding to establish centers wherever possible. (long-term strategy)
- Encourage funding agencies, foundations, etc., to fund centers of expertise in health communication research, in addition to centers for excellence. (long-term strategy)

Assessment

- Confirm consensus on core criteria to identify centers. (short-term strategy)
- Confirm the reporting mechanism to provide data for the objective. (short-term strategy)
- Establish a mechanism to track and evaluate contributions made by centers for excellence, such as the development of new health communication knowledge (e.g., models, theories); new health communication research methods (e.g., instruments, strategies); health communication practices and policies; and collaborations. (short-term strategy)
- Develop credential or accreditation mechanisms for centers. (long-term strategy)

Infrastructure Development

- Establish a panel of experts to oversee the development of research centers for excellence. (short-term strategy)
- Establish a resource-sharing or consultation mechanism (e.g., a health communication research consortium) to provide added resources for developing centers. (short-term strategy)
- Take advantage of the interest and momentum generated by the NCI RFA on CECCRs and develop ways to help worthy applicants who were not funded to establish centers. (short-term strategy)
- Have a debriefing miniconference among NCI center grant applicants to explore strategies for collaborating and maintaining the momentum. (short-term strategy)
- Create a think tank of key scholars, administrators, and politicians to develop strategies for establishing centers. (short-term strategy)

- Develop networks, formal and informal, to lobby or work for center funding or programs. (long-term strategy)
- Create a virtual center incubator to facilitate the establishment of centers. (long-term strategy)
- Develop best practice guidelines for conducting quality health communication research. (long-term strategy)
- Encourage the National Institutes of Health (NIH) to develop a new mechanism to fund establishment of infrastructure units to promote health communication research. (long-term strategy)
- Establish collaborative infrastructures to fund centers and set research priorities. (long-term strategy)

Publication

- Create special issues of journals to promote centers. (long-term strategy)

Training and Professional Development

- Establish a health communication fellows program collaboratively among key professional groups (International Communication Association, National Communication Association, American Public Health Association). (short-term strategy)
- Establish training of researchers as a major priority among existing centers, and fund training mechanisms (e.g., postdoctorate). (long-term strategy)
- Use cooperative research agreements to facilitate training and research in health communication. (long-term strategy)

Recognition

- Involve the major professional associations in the development of recognition awards for outstanding projects, distinguished individuals, and model programs or curricula. (short-term strategy)
- Establish a prestigious center award for recognized excellence in health communication research, accompanied by a substantial grant funded by industry or foundation sources. (short-term strategy)

ACTION STEPS

Establish a working group or identify an existing advisory body to promote the centers objective. NCI would coordinate this group, which would comprise representatives from

- Professional associations
- Government agencies
- Healthcare industries
- Foundations
- Patient advocacy groups

Work with existing funding sources to encourage center funding.

Develop a Web site designed to promote and facilitate the establishment of centers. The site and related support mechanisms would

- Organize existing resources to provide technical assistance to those willing to pursue the establishment of centers.
- Provide grant-writing assistance and grant application models.
- Facilitate interdisciplinary collaboration among individuals and institutions.
- Provide consultation mechanisms for easier access to needed research and administrative expertise.
- Foster involvement of knowledgeable individuals in the peer review processes related to funding mechanisms.

Establish a formal mentoring system for health communication researchers to feed developing centers with quality research personnel.

Establish formal networks of opinion leaders via print, electronic, and interpersonal means to diffuse information to health communication researchers.

Partner with other agencies and initiatives to ensure that health communication research is incorporated and research centers are involved.

Establish formal linkages with State and local public health agencies to facilitate the involvement of established or developing health communication research centers at these levels.

RESOURCES NEEDED

NCI already has dedicated substantial resources to the creation, support, and ongoing assessment of CECCRs. Additional resources may be needed to track non-NCI-funded centers and certainly to establish additional centers.

The primary resource needs are associated with the functions to be carried out by centers, as described in the health communication chapter in *Healthy People 2010:*

> These centers should provide expert staff, model curricula with core competencies in health communication and media technologies, appropriately equipped media labs, research seminars, continuing education and distance learning courses, and training and placement programs to expand the pool of health communication professionals and health professionals with communication skills. The centers also could create databases that would catalog items such as formative and outcomes research studies and reports and could partner with existing governmental dissemination networks to make data publicly available. Centers for excellence in health communication could be funded through Federal grants, foundations, or private-sector healthcare organizations.

LEAD ORGANIZATIONS AND RESPONSIBILITIES

The organizations that should take the lead in moving this objective forward are as follows:

- NCI will work with the Office of Disease Prevention and Health Promotion to develop a collaborative process to promote the centers concept, engage stakeholders, encourage funding, and provide ongoing assessment and recognition of progress.
- The stakeholders mentioned earlier also should be involved, to the extent possible, to provide critical guidance and to engender widespread support for the overall effort.

TIMEFRAME FOR ACTION STEPS

The timeframe recommended for the development of action plans for this objective is outlined below.

First 1 to 2 years

- Identify the mechanism within NCI to coordinate the effort to promote the establishment of centers for excellence (see Action Steps above).
- Create mechanisms to educate the field, funding agencies, and the public about the importance of centers.
- Encourage special issues of journals to promote centers.
- Convene stakeholders to develop strategies for promoting and developing more centers.
- Collaborate with other agencies to get center grant funding set at a high priority.
- Have a debriefing miniconference among the NCI center grant applicants to explore strategies for collaborating and keeping the momentum going.
- Work with NCI center grant applicants to encourage submission for research program projects (PO1), postdoctorate funding, training grants, etc., to move toward center status.
- Promote the need for centers within and across professional associations, at conferences, and at professional meetings.
- Promote collaboration among professional associations for joint efforts to create and support health communication research centers.
- Establish a resource-sharing or consultation mechanism (e.g., a health communication research consortium and Web site) to provide added resources for developing centers.
- Create a think tank of scholars, administrators, and politicians to develop strategies for establishing centers.
- Establish a health communication fellows program collaboratively among professional groups (e.g., International Communication Association, National Communication Association, American Public Health Association).

Longer term activities

- Encourage increased funding to establish centers wherever possible.
- Establish collaborative infrastructures to fund centers and set priorities.
- Develop networks, formal and informal, to lobby for center support.
- Encourage interagency collaboration to fund centers.
- Use cooperative research agreements to facilitate training and research in health communication.
- Encourage NIH to develop a new mechanism to fund the establishment of infrastructure units to promote health communication research centers.
- Encourage the funding of "centers of expertise" in health communication research, as well as centers for excellence.
- Develop best practice guidelines for conducting quality health communication research.
- Create a virtual center incubator to facilitate the establishment of centers.
- Establish training of researchers as a major priority among existing centers and fund training mechanisms (e.g., postdoctorate, personnel agreements).

FOR MORE INFORMATION

NCI Centers of Excellence in Cancer Communications Research
http://dccps.nci.nih.gov/hcirb

Anderson JG, Aydin CE, Jay SJ, eds. *Evaluating health care information systems.* Thousand Oaks, CA: Sage Publications, 1994.

Backer TE, Rogers EM, Sopory P. *Designing health communication campaigns: what works?* Newbury Park, CA: Sage Publications, 1992.

Finnegan JR Jr, Viswanath K. Health and communication: medical and public health influences on the research agenda. In: *Communication and health: systems and applications*, Ray EB, Donohew L, eds. Hillsdale, NJ: Lawrence Erlbaum Associates, 1990.

Harris LM, ed. *Health and the new media: technologies transforming personal and public health.* Mahwah, NJ: Lawrence Erlbaum Associates, 1995.

HHS. *Healthy People 2010.* 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

Institute of Medicine and National Research Council. *Ensuring quality cancer care.* Washington, DC: National Academy Press, 1999.

Jackson LD, Duffy BK, eds. *Health communication research.* Westport, CT: Greenwood, 1998.

Kim P, Eng TR, Deering MJ, et al. Published criteria for evaluating health-related Web sites: review. *Br Med J* 1999; 318:647-9.

Kreps GL, Bonaguro EW, Query JL Jr. The history and development of the field of health communication. In: *Health communication research*, Jackson LD, Duffy BK, eds. Westport, CT: Greenwood Press, 1998.

National Cancer Institute. *Making health communications work.* Pub. No. NIH 89-1493. Washington, DC: U.S. Department of Health and Human Services, 1989.

Ratzan SC, ed. Health communication: challenges for the 21st century. Special issue. *Amer Behav Sci* 1994;38(2).

Robinson TN, Patrick K, Eng, TR, et al., for the Science Panel on Interactive Communication and Health. An evidence-based approach to interactive health communication: a challenge to medicine in the information age. *J Amer Med Assoc* 1998; 280:1264-9.

Science Panel on Interactive Communication and Health. *Wired for health and well-being: the emergence of interactive health communication*, Eng TR, Gustafson DH, eds. Washington, DC: U.S. Department of Health and Human Services, 1999.

Viswanath K, Finnegan JR. Community health campaigns and secular trends: insights from the Minnesota Heart Health Program and Community Trials in Heart Disease Prevention. In: *Public health communication: evidence for behavior change*, Hornick R, ed. New York: Erlbaum, 2002.

OBJECTIVE 11-6
HEALTHCARE PROVIDERS' COMMUNICATION SKILLS

DRAFTERS

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TEXT OF OBJECTIVE

Increase the proportion of persons who report that their healthcare providers have satisfactory communication skills.

SCOPE

The objective is intended to represent an important aspect of provider-patient communication but cannot encompass all issues raised by and related to the subject. The objective means to serve the specific purpose of providing data on progress for select factors related to provider-patient communication and the general purpose of stimulating discussion about a wide range of provider-patient communication issues.

MEASUREMENT

The objective is measurable. It seeks to determine how patients evaluate their healthcare providers in terms of behaviors important to provider-patient communication. Data are collected as part of the Medical Expenditure Panel Survey (MEPS) administered by the Agency for Healthcare Research and Quality (AHRQ). The items from MEPS are

In the last 12 months,

- How often did doctors or other health providers listen carefully to you?
- How often did doctors or other health providers explain things in a way you could understand?
- How often did doctors or other health providers show respect for what you had to say?
- How often did doctors or other health providers spend enough time with you?

Response categories for each item are Never, Sometimes, Usually, Always, and "I had no visits in the last 12 months." Current data are reported in Table 4. Data from each item are reported separately rather than aggregated for a single number.

The explicit purpose of the objective is to ensure that patients have the opportunity to assess a key element of the healthcare encounter: communication with their care providers. The larger goal of the objective is to ensure steady improvement in the capacity of patients and providers to communicate with each other in support of better patient outcomes. It is recognized that provider-patient communication is a multidimensional phenomenon that impacts on all aspects of care and patient outcomes, which makes it difficult to assess with a single measure. The four MEPS items provide data on core dimensions of provider-patient communication but are certainly not exhaustive. Measures of additional dimensions would enhance our understanding of the dynamic between patients and providers, and the development of additional measures should be an important part of future activities in this area.

ISSUES PERTAINING TO MEASUREMENT

As currently stated, the objective measures patients' assessment of providers' communication skills. Such an assessment may actually translate into a measure of satisfaction, which is less

TABLE 4. DATA FOR OBJECTIVE 11-6

Patients reporting that doctors or other health providers always:	Baseline 2000 (Percent)	Target 2010 (Percent)
11-6a. Listen carefully	56	64
11-6b. Explain things so you can understand	58	65
11-6c. Show respect	58	65
11-6d. Spend time	45	52

Source: Medical Expenditure Panel Survey, AHRQ, 2000

robust than other possible measures. An ideal measure would allow actual assessment of skills according to predefined criteria. The issue should be less one of satisfaction and more one of capacity- and skill-building, both for patients and providers. As patients and providers increase their abilities to communicate with each other, it is anticipated that a host of valued patient outcomes also will improve.

Similar to the objective on health literacy, issues of limited literacy, proficiency in English, and cultural and linguistic differences are critical considerations for the development of appropriate assessments of patients' and providers' communication skills as well as the design of interventions to improve communication skills. There is growing recognition that being able to comprehend health information and services is critical to all aspects of personal health management. There is also growing acceptance that a multicultural society that values health for all requires the healthcare system and providers to provide culturally and linguistically competent health care. Even if assessments of patient-provider communication are conducted in the appropriate languages for the patients and the providers, instruments that are not sufficiently sensitive to limited literacy skills and cultural and linguistic differences may mischaracterize both groups' ability to communicate with each other.

An additional consideration for assessment is that the items from MEPS are not specific enough in identifying which healthcare providers from which disciplines have which skill levels. Patients are likely to assess the communication skills of physicians differently from those of nurses, and differently among specialties. The current MEPS questions do not allow such distinctions. More precise data on disciplines and occupational categories would be important to allow the data to inform the design of effective interventions for skill-building for patients and providers from different disciplines and with distinct roles in healthcare processes.

STATE OF KNOWLEDGE ABOUT ISSUES REPRESENTED BY THE OBJECTIVE

The growing body of literature linking communication skills to a host of valued patient outcomes, including satisfaction, adherence, and positive health indicators, is drawing increasing attention to the centrality of the interpersonal skills of healthcare providers to the delivery of quality medical care. As a result, communication skills are increasingly regarded on a par with other technical areas of medical practice for which proficiency is expected (Lipkin et al., 1995). Within this context, "patient-centeredness" in medical communication curricula has become the shorthand reference to the constellation of skills most often regarded as a critical element in the delivery of quality interpersonal care (Lipkin et al., 1995; Mead and Bower, 2000; Tressolini and Pew-Fetzer Task Force, 1994). Patient-centered skills are those that are responsive to patients' values, needs, and preferences and commonly include data-gathering skills (e.g., use of open-ended questions, particularly in the psychosocial domain), relationship skills (e.g., use of empathy, reassurance, support, and emotional responsiveness), partnering skills (e.g., paraphrasing, asking for patient opinion, negotiation, and joint problemsolving), and counseling skills (e.g., informativeness, persuasion) (Lazare et al., 1995; Roter, 2000).

Although the specification of patient-centered skills has its origin in the medical literature (Engel, 1977; McWhinney, 1989), the skills are equally relevant and applicable to all healthcare providers, including those representing the full spectrum of allied health fields. Furthermore, patients have a role in improving the quality of their medical and dental interactions by increasing their own communication skills.

Physician and patient training in communication skills. A limitation of the empirical literature evaluating the acquisition of communication skills, or the link between these skills and patient outcomes, has been the literature's primary reference to physicians or physicians in training. Much of what has been learned, however, is likely to apply to other healthcare providers as well.

Many commentators have noted the ironic fact that physicians perform thousands of medical interviews during their career with only minimal formal training in communication skills. Fortunately, evidence supports that training in the area is effective and long-lasting, with at least one study demonstrating that skills were maintained as long as 5 years after training was complete (Maguire et al., 1986). Whereas communication and interpersonal skills training is now considered an essential component of medical school criteria by the Liaison Committee on Medical Education, implementation of such training remains highly variable (Association of American Medical Colleges [AAMC], 1999). Communication and interpersonal skills have also been deemed one of the required competencies for resident physicians (Accreditation Council for Graduate Medical Education [ACGME]) and practicing physicians (American Board of Medical Specialties [ABMS]), a development that will extend teaching and assessment programs across the continuum of medical education and practice. Medical students, residents, and practicing physicians will likely benefit from attention to a framework that highlights essential communication tasks (Makoul, 2001).

The length and format of communication training programs vary a great deal, with some training programs offering as few as 4 hours of instruction and others with a developed curriculum of 40 hours or more. Although very short programs have failed to demonstrate a successful training effect in the past (Levinson and Roter, 1993), more recent use of interactive CD-ROM technology to tailor direct feedback to residents on interviewing performance are very promising and time-efficient (Roter and Larson, 2002).

In contrast to the existence of many programs aimed at physicians and many published evaluations of such programs, relatively little research has tried to intervene with patients to improve the communication process. The earliest of these experimental intervention studies was a waiting-room intervention designed to increase the number of questions patients ask (Roter, 1977). This proved successful in doubling the number of questions patients asked and led to a significant increase in study patients' level of internal locus of control and improvements in appointment-keeping over a 6-month period.

A related, but more elaborate, waiting-room intervention was developed by Greenfield and colleagues (1988) that not only influenced patients' communication behaviors (experimental patients elicited more information from physicians, talked more, and were more assertive) but had significant effects on health outcomes, including reduced blood sugar, reduced blood pressure, reduced patients' reports of functional limitations (mobility, role functions, physical activities), and improved patients' perceptions of their overall health (Greenfield et al., 1988; Kaplan et al., 1989).

Adherence with therapeutic recommendations. Not surprisingly, research has found correlations between physician-patient communication and adherence. Patients are more adherent when their physicians deliver more information, ask more questions about adherence (but fewer questions overall), and engage in more positive talk (Hall et al., 1988). Patients of physicians who were more sensitive to nonverbal cues (as measured with a standardized test) were more likely to keep their scheduled appointments than were patients of less sensitive physicians (DiMatteo et al., 1986).

Clinical outcomes and quality of life. The amount of information that physicians provide to patients, partnership building, and emotional rapport and support are related to a range of health outcomes, such as improvements in emotional health, symptom resolution, physical functioning and quality of life assessments, physiological indicators of disease management (e.g., blood pressure, blood sugar), and pain control (Stewart, 1996). For example, blood pressure control improved more if patients were allowed to tell their whole story to their doctor and the doctor provided more information to the patient (Orth et al., 1987), and emotional health status improved more over time when the physician's communication style included more psychosocial counseling (Roter et al., 1995). Reductions in emotional distress and measures of depression, as well as improvement in coping, also have been associated with patient-centered communication (Stewart, 1996).

STAKEHOLDERS AND THE STATUS OF THEIR ACTIVITIES

Eight broad groups of stakeholders directly share interests in the improvement of clinical communication, as described below.

- **Consumer and patient advocacy organizations.** Consumer and patient advocacy groups have long recognized the significance of communication in the delivery of quality care and directly benefit from improved communication practices. Indeed, consumer demand for interpersonal competence can act as a catalyst for other stakeholder organizations to value, reward, and adopt higher standards of communication skills for providers. These groups can also be important sources of information on the relevant literacy, cultural, and linguistic considerations for different populations that should be part of assessments and interventions.
- **Professional societies.** Professional societies are responsible for the communication of professional values and the establishment of normative practice. They also provide vision and future direction to the profession through continuing education and advocacy services. Members of these organizations often hold influential positions in training, policy, and service delivery organizations. Many professional societies have an interest in patient-provider communication. Two professional groups that are particularly noteworthy in their primary dedication to education and research related to medical communication are the American Association of

Patients and Providers (AAPP) and Advancing Communication Skills in Oncology through Research and Education (ACORE). AAPP has developed a train-the-trainers approach to the teaching of medical communication and conducts national and regional training retreats. ACORE is a newly formed organization designed to address the particular training and research issues relevant to communication between healthcare providers and cancer patients and their families.

- **Academic training programs.** Professional training programs (e.g., medical, dental and pharmacy schools, residency programs, nursing schools) set and monitor performance standards for programs and institutions; both AAMC and ACGME have highlighted the importance of teaching and assessing interpersonal and communication skills. These programs implement and develop curricula based on performance standards and are responsible for certifying that individuals have met an acceptable standard of competency throughout the training period. The National Board of Medical Examiners (NBME) and the Federation of State Medical Boards have approved the inclusion of a clinical skills exam, which includes communication with patients, in the U.S. Medical Licensing Examination, beginning in 2004. The Educational Commission for Foreign Medical Graduates currently administers a clinical skills test, one component of which addresses key dimensions of doctor-patient communication (AAMC, 1999).

- **Accreditation organizations, governing bodies, and boards.** A variety of organizations are responsible for credentialing in areas relevant to communication skills. These include bodies that credential schools (Liaison Committee on Medical Education) and hospitals (Joint Commission on Accreditation of Healthcare Organizations) and those that directly credential providers (specialty boards). Each of these bodies reviews and accredits programs and providers on a regular basis in accordance with explicit standards. The American Board of Internal Medicine (ABIM) is an influential body and a leader in setting standards for practitioners. This is just one of more than 20 different specialty boards encompassed by the American Board of Medical Specialties (ABMS), which are now committed to focusing on communication and interpersonal skills as a required competency for practicing physicians.

- **Research and education conducted by foundations, universities, and Government agencies.** These institutions set priorities for the research agenda and drive new initiatives. They are likely to establish and evaluate performance standards that will be implemented by training and credentialing bodies and adopted by health delivery organizations. Among notable activities, NCI has spearheaded research in health communication with the establishment of its Health Communication and Informatics Research Branch. The Branch has issued numerous program announcements and supported funding mechanisms dedicated to health communication, including the recent Consumer/Provider Communication Research Symposium (held in January 2002). The Robert Wood Johnson Foundation similarly has developed program announcements and has made commitments to fund research on enhancing patient activation and health communication. The Pew-Fetzer Task Force on Advancing Psychosocial Health Education produced an important report in the specification of relationship-centered care (Tressolini and Pew-Fetzer Task Force, 1994).

- **Policymakers.** Legislative and regulatory bodies on both the State and national level are influential in funding research, encouraging translational research, and speeding the adoption of good practices. Legislative work regarding the Patient Bill of Rights is indicative of interest in this arena.

- **Training industry.** University and private-sector efforts are already devoted to meeting basic and continuing educational needs of health providers. The industry has historically responded to changing educational needs of students, particularly in response to changes in licensure and certification exams.

- **Healthcare delivery organizations, health plans, and purchasers such as employers and unions.** Quality of care is highly valued in purchasing decisions. Communication skills are increasingly recognized as a quality indicator with substantial links to patient satisfaction, adherence, and positive health outcomes.

FACTORS THAT CAN INFLUENCE CHANGE

Barriers. Increasing pressures to deliver more services in less visit time and competition for the delivery of more technical services (the "one more thing" syndrome) may diminish providers' responsiveness to continuing medical education (CME) programs to improve communication (Mechanic et al., 2001). This is particularly so as skill acquisition takes time (usually time away from clinical practice) and money associated with the provision of trained faculty and expertise. Additional barriers may include providers' lack of appreciation or awareness of multicultural relevant aspects of communication or specific needs of low-literacy patients. The lack of health information and services appropriate to the literacy, cultural, and linguistic needs of different populations is a major barrier to progress.

Leverage. Improved communication may afford some protection in regard to malpractice. Evidence shows that patients and families are more likely to sue a physician when faced with a bad outcome if they feel that the physician failed to communicate in a timely and open manner or was uncaring or indifferent (Beckman et al., 1994). One study documented differences in routine communication associated with a history of malpractice litigation. This study found that doctors who had never been sued had longer visits, engaged in more laughter, were more likely to orient the patient to what to expect in regard to the flow of the visit, and used more partnership-type exchanges (e.g., asking for the patient's opinion, enhancing patient's understanding of what was said and expectations for the visit, showing interest in patient disclosures, paraphrasing and interpreting what the patient said) than physicians who had been sued (Levinson et al., 1997).

Moreover, improved medical communication is associated with valued patient outcomes, including disease control (Stewart,

1996) and reductions in healthcare delivery costs, particularly those associated with disenrollment (Kaplan et al., 1996).

STRATEGIES AND SOLUTIONS

- Broaden Objective 11-6 to reflect capacity-building and skill assessment rather than patient satisfaction with communication skills.
- Increase attention to skill development during medical training; support the inclusion of communication skills by accrediting bodies; develop CME programs, particularly Web-based, interactive formats that can maximize access and individualized tailoring.
- Mobilize activities across the nine stakeholder groups and develop crosscutting efforts where possible.

ACTION STEPS

Consumer and Patient Advocacy Organizations

- Build a broad consortium of advocacy groups that share a commitment to the improvement of providers' interpersonal skills.
- Encourage advocacy organizations to focus on credentialing of healthcare providers; educate them to the fact that requirements exist for medical, dental, and pharmacy students, and residency programs as well as for certification of practicing healthcare providers.
- Promote the development of patients' communication skills with their healthcare providers.
- Promote the inclusion of relevant literacy, cultural, and linguistic considerations in communication assessments and interventions for patients and providers.

Professional Societies

- Encourage and support the provision of CME programs that address providers' interpersonal skills.
- Emphasize training providers to address literacy, cultural, and linguistic factors, particularly for high-risk, vulnerable populations with the poorest health status and access to information and services.

- Promote the inclusion of relevant literacy, cultural, and linguistic considerations in communication assessments and interventions for patients and providers.

Academic Training Programs

- Encourage AAMC to periodically monitor and report on the status of communication skills education in medical schools.
- Encourage ACGME to periodically monitor and report on the status of communication skills education in residency programs.
- Support NBME's implementation of a standardized patient exam, which will motivate medical schools to enhance communication skills training for their students.
- Support ABMS efforts to have medical specialty boards assess interpersonal and communication skills as a core competency.
- Emphasize training providers to address literacy, cultural, and linguistic factors, particularly for high-risk, vulnerable populations with the poorest health status and access to information and services.
- Promote the inclusion of relevant literacy, cultural, and linguistic considerations in communication assessments and interventions for patients and providers.

Accreditation Organizations, Governing Bodies, and Boards

- Provide CME credits for communication training to providers through a variety of professional venues.
- Encourage State boards to include communication as a requirement for recertification. The American Medical Association has the list of all current State requirements.
- Emphasize training providers to address literacy, cultural, and linguistic factors, particularly for high-risk, vulnerable populations with the poorest health status and access to information and services.

Research and Education: Foundations, Universities, and Government Agencies

- Build research and programmatic collaborations across organizations.

- Evaluate existing programs for gaps and opportunities to support research and education to improve communication, particularly related to the role of literacy, culture, and language in patient-provider communication.

Policymakers: Legislative and Regulatory Bodies

- Work with professional societies and consumer and patient advocacy groups to support health policy and financing initiatives to adequately reimburse clinicians for time devoted to patient counseling and education (e.g., Medicare standards and reimbursement for patient-provider telephone or e-mail consultations).

Training Industry

- Work with the training industry and university programs to provide appropriate CME vehicles to disseminate good practices.
- Develop materials appropriate across the training spectrum.
- Emphasize training providers to address literacy, cultural, and linguistic factors, particularly for high-risk, vulnerable populations with the poorest health status and access to information and services.

Healthcare Delivery Organizations, Health Plans, and Purchasers Such as Employers and Unions

- Work through large group purchasers (e.g., unions, corporations) to assess quality performance in communication skills.
- Work with delivery organizations to identify and provide incentives to employees for good communication practices.
- Work with delivery organizations to conduct research to test the impact of improved communication on patient and provider satisfaction.
- Work with delivery organizations to include relevant literacy, cultural, and linguistic considerations in assessments of system and provider performance.

Association of American Medical Colleges. *Report III: Contemporary issues in medicine: communication in medicine.* Medical School Objectives Project. Washington, DC: Association of American Medical Colleges, 1999.

Beckman HB, Markakis KM, Suchman AL, Frankel RM. The doctor-patient relationship and malpractice: lessons from plaintiff depositions. *Arch Int Med* 1994;154(12):1365-70.

DiMatteo MR, Hays RD, Prince LM. Relationship of physicians' nonverbal communication skills to patient satisfaction, appointment noncompliance, and physician workload. *Health Psych* 1986; 5:581-94.

Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977;196:129-36.

Greenfield S, Kaplan SH, Ware E Jr, Yano EM, Frank HJL. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Int Med* 1988;3:448-57.

Hall JA, Roter DL, Katz NR. Meta-analysis of correlates of provider behavior in medical encounters. *Med Care* 1988;26:657-75.

Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE. Characteristics of physicians with participatory decision making styles. *Ann Intern Med* 1996;124:497-504.

Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care* 1989;27:S110-27.

Lazare A, Putnam SM, Lipkin M. Three functions of the medical interview. In: *The medical interview: clinical care, education, and research*, Lipkin M, Putnam S, Lazare A., eds. New York: Springer-Verlag, 1995.

Levinson W, Roter DL. The effects of two continuing medical education programs on communication skills of practicing primary care physicians. *J Gen Inter Med* 1993;8:318-24.

Levinson W, Roter DL, Mullooly J, Dull V, Frankel R. Doctor-patient communication: a critical link to malpractice in surgeons and primary care physicians. *JAMA* 1997;277:553-9.

Lipkin M, Putnam S, Lazare A, eds. *The medical interview: clinical care, education, and research.* New York: Springer-Verlag, 1995.

Maguire P, Fairburn S, Fletcher C. Consultation skills of young doctors: benefits of feedback training in interviewing as students persist. *Br Med* J 1986;292:1573-6.

Makoul G. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. *Acad Med* 2001;76(4):390-3.

McWhinney I. The need for a transformed clinical method. In: *Communicating with medical patients*, Stewart M, Roter DL, eds. Newbury Park, CA: Sage, 1989.

Mead N, Bower P. Measuring patient-centeredness: a comparison of three observation-based instruments. *Patient Educ Coun* 2000;39:71-80.

Mechanic D, McAlpine DD, Rosenthal M. Are patients' office visits with physicians getting shorter? *N Eng J Med* 2001; 344:198-204.

Orth JE, Stiles WB, Scherwitz L, Hennrikus D, Vallbona C. Patient exposition and provider explanation in routine interviews and hypertensive patients' blood pressure control. *Health Psych* 1987;6:29-42.

Roter DL. The enduring and evolving nature of the patient-physician relationship. *Patient Educ Coun* 2000;39:5-15.

Roter DL. Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction, and compliance. *Health Educ Mono* 1977;50:281-315.

Roter DL, Hall JA, Kern DE, Barker LR, Cole KA, Roca RP. Improving physicians' interviewing skills and reducing patients' emotional distress: a randomized clinical trial. *Arch Int Med* 1995;155:1877-84.

Roter DL, Larson S. The Roter Interaction Analysis System (RIAS): utility and flexibility for analysis of medical interactions. *Patient Educ Coun* 2002;46:243-51.

Stewart MA. Effective physician-patient communication and health outcomes: a review. *Can Med Assoc* J 1996;152:1423-33.

Tressolini CP, Pew-Fetzer Task Force. *Health professions education and relationship-centered care.* San Francisco: Pew Health Professions Commission, 1994.

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APPENDIX
EXAMPLES OF STAKEHOLDERS INVOLVED IN TECHNOLOGY DIFFUSION AND INTERNET ACCESS INITIATIVES

Stakeholder Category	Stakeholder	Contact Information	Comments
Application Developer	Apple	www.apple.com/education/mobilecomputing	Apple's iBook Wireless Mobile Lab initiative in schools may allow home computer access to students who are able to bring their wireless laptops home.
Application Developer, Corporate Foundation	AOL Time Warner Foundation	www.aoltimewarnerfoundation.org	The AOL Time Warner Foundation seeks to improve access to communications and information technology and make them more widely available. The foundation focuses its giving in four core areas: the digital divide, civic engagement, kids, and arts in the community.
Application Developer, Corporate Foundation	Intel Corporation and Foundation	www.intel.com/community	The Intel Foundation funds programs that advance math and science education, promote women and underrepresented minorities entering science careers, and increase public understanding of technology.
Application Developer, Corporate Foundation	Microsoft Corporation	www.microsoft.com/giving/display.asp?page=expanding www.nten.org	Microsoft Giving focuses on creating greater access to information technology in disadvantaged communities worldwide. The Microsoft Corporation makes grants of cash, software, and technical support to nonprofit organizations worldwide to help bring information technology to people and communities. Npower is the incubator of the Nonprofit Technology Enterprise Network.

Stakeholder Category	Stakeholder	Contact Information	Comments
Corporate Foundation	ADC Foundation	www.adc.com/aboutadc/adcfoundation/programs/#technology	The ADC Foundation seeks to support innovative educational programs and organizations that support excellence in science and technology education and expand telecommunications access for the disadvantaged.
Corporate Foundation	BellSouth Foundation	www.bellsouthfoundation.org/about/index.asp	The BellSouth Foundation provides grants to improve outcomes for elementary and secondary students in select states. It also sponsors a health and education initiative.
Corporate Foundation	Digital Blackboard Foundation (formerly Washington Software Foundation)	www.learningspace.org/digitalblackboard	The Digital Blackboard Foundation supports outstanding teachers who open opportunities for students and close the education gap in schools and communities at risk. The foundation works to incorporate classroom technology into new educational practices to help these teachers improve students' performance.
Corporate Foundation	eBay Foundation	www.pages.ebay.com/community/aboutebay/foundation/history.html	The eBay Foundation's primary focus has been to support organizations that assist people in reaching their full potential through the creative application of technology.
Corporate Foundation	NEC Foundation of America	www.necfoundation.org	The NEC Foundation of America makes cash grants to nonprofit organizations with national impact in science and technology education, primarily at the secondary level, or the application of technology to assist people with disabilities.

Stakeholder Category	Stakeholder	Contact Information	Comments
Corporate Foundation	Verizon Foundation (formerly Bell Atlantic Foundation)	http://foundation.verizon.com	The Verizon Foundation focuses on literacy, the digital divide, workforce development, community technology development, and employee volunteerism.
Federal Committee	Web-based Education Commission	www.hpcnet.org/webcommission	The mission of the Web-based Education Commission was to recommend actions to help ensure that all learners have full and equal access to the capabilities of the World Wide Web, and to ensure that online content and learning strategies are affordable and meet the highest standards of educational quality.
Federal Funding	AmeriCorps	www.americorps.org/digital/index.html	AmeriCorps is a volunteer organization that brings the Internet to lower-income families, people of color, and those who live in rural areas. Members are helping Americans acquire the skills to use the Internet through one-on-one instruction to children and adults.
Federal Funding	Institute of Museum and Library Services (IMLS)	www.imls.gov	IMLS is an independent Federal agency supporting the Nation's 10,000 museums and 122,000 libraries. IMLS grant programs fund projects that promote literacy, provide free public access to the Internet, train individuals to use computers effectively, and provide educational and vital content on the Web.

Stakeholder Category	Stakeholder	Contact Information	Comments
Federal Government	U.S. Department of Agriculture (USDA), Computer Donations Program, Computers for Learning	www.lsc.usda.gov/computers.asp	USDA's Computer Donations Program receives excess computers from Federal offices and repairs or refurbishes them for donations to schools. The Computers for Learning program places computers in classrooms and prepares children to be technologically apt. Children who are schooled at home are eligible to receive a computer.
Federal Government	U.S. Department of Agriculture, Research on Rural Telecommunications, Economic Research Service (ERS)	www.ers.usda.gov	The Research on Rural Telecommunications Branch of ERS works on improving rural infrastructure. Recently, ERS conducted an assessment of Internet access and use by farmers in rural areas.
Federal Government	U.S. Department of Agriculture, Rural Utilities Service (RUS)	www.rurdev.usda.gov/rus	RUS helps rural America finance electric, telecommunications, water, and wastewater projects and makes loans and grants for rural distance learning and telemedicine projects, particularly in rural areas with populations of fewer than 5,000 people. In addition, RUS is greatly expanding the efforts to bring broadband technology into rural households.
Federal Government	U.S. Department of Commerce, National Telecommunications and Information Administration (NTIA)	www.ntia.doc.gov/otiahome/top/index.html	NTIA administers the Technology Opportunities Program (TOP) to bring digital networks to communities in the United States. This grant program provides matching grants to State, local, and tribal governments and nonprofit entities for model projects that demonstrate innovative uses of digital network technologies in underserved communities.

Stakeholder Category	Stakeholder	Contact Information	Comments
Federal Government	U.S. Department of Education, Enhancing Education through Technology, No Child Left Behind	www.ed.gov/offices/OESE/SST/edtech.html#grant	The No Child Left Behind program of the U.S. Department of Education gives grants for computer technology and Internet access to schools and community centers.
Federal Government	U.S. Department of Education, Office of Educational Technology	www.ed.gov/Technology/digdiv.html	The U.S. Department of Education's Office of Educational Technology provides substantial funding to help American schools and communities bridge the digital divide, reducing inequities in access to information technology and the Internet.
Federal Government	U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA)	http://telehealth.hrsa.gov	HRSA's Office for the Advancement of Telehealth funds telemedicine projects in the United States to help ensure equitable access to comprehensive, quality health care for all.
Federal Government	U.S. Department of Housing and Urban Development (HUD)	www.hud.gov/neighborhoodnetworks	HUD established Neighborhood Networks—innovative private and public partnerships establishing computer-based multiservice centers to help people in public and assisted housing learn critical computer skills and prepare for 21st-century jobs.

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Federal Government	U.S. Department of Labor, Employment and Training Administration (ETA)	www.doleta.gov	ETA seeks to ensure that American workers, employers, students, and those seeking work can obtain information, employment services, and training (including technology training).
Federal Government, Federal Funding	U.S. Department of Education, Community Technology Center Program	www.ed.gov/offices/OVAE/AdultEd/CTC/index.html	The Community Technology Center program funds local community technology centers that demonstrate the educational value of technology in urban, rural, and economically distressed communities.
Independent Foundation	Benton Foundation	www.benton.org	The Benton Foundation raises public awareness, understanding, and involvement in communications policy issues by educating the public and decisionmakers about the current issues involving the rapidly changing communications landscape. Benton's Digital Divide Network chronicles the issues of the digital divide and provides "best practice" stories of efforts to reduce the digital divide, including those to increase home access to the Internet.
Independent Foundation	Bill & Melinda Gates Foundation	www.gatesfoundation.org	The Bill & Melinda Gates Foundation is dedicated to improving people's lives through increasing health and learning. It has three focus areas: education, libraries, and public access to information. Currently, the Community Access to Technology grant program is designed to assist nonprofit organizations in Washington State to deliver access to information technologies to State residents.

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Independent Foundation	California HealthCare Foundation	www.chcf.org	The California HealthCare Foundation focuses on several issues, including managed care, the uninsured, health policy and regulation, healthcare quality, and public health. The foundation has sponsored several analyses of privacy issues related to health Web sites, a series of reports on the future of e-health, and an "eHealth Reports" feature on its Web site.
Independent Foundation	Case Foundation, PowerUP	www.powerup.org /index.shtml	The Case Foundation provided $10 million to start PowerUP, a partnership of more than a dozen nonprofit organizations, major corporations, and Federal agencies to give underserved children access to technology and guidance on how to use it. The partnership focuses on increasing access to technology within schools and community centers.
Independent Foundation	Community Technology Foundation of California	www.zerodivide .org	The Community Technology Foundation of California works to bring existing and new communications and information technologies to California's underserved communities. The foundation's primary goal is to increase the access of underserved populations to basic and advanced telecommunications services as well as to provide the necessary education and training to use these services.

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Independent Foundation	J.C. Downing Foundation	www.jcdowning.org	The J.C. Downing Foundation supports efforts and projects in five program areas: education and human development, environmental research and preservation, fine arts, sports and athletics, and technology and communication.
Independent Foundation	John and Mary R. Markle Foundation	www.markle.org	The John and Mary R. Markle Foundation promotes the development of communications programs that addresses public needs. A recent initiative involved expanding efforts for increasing household Internet access, resulting in the publication *Toward a Framework of Internet Accountability.*
Independent Foundation	Kellogg Foundation	www.wkkf.org	The Kellogg Foundation seeks to increase and support equal access to information and electronic media through education and policy support. Special attention is focused on vulnerable populations, especially youth.
Independent Foundation	Paul G. Allen Virtual Education Foundation	www.pgafoundations.com	The Paul G. Allen Virtual Education Foundation seeks to advance the development and growth of online learning experiences. The foundation primarily funds projects to design, test, produce, and evaluate digital content for education, including multimedia instructional materials and instructional software.

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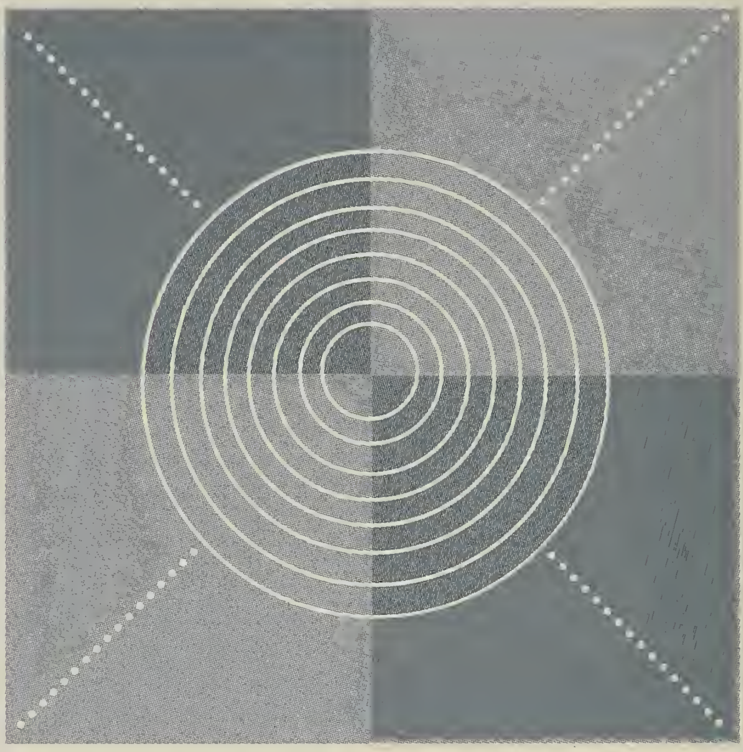
Independent Foundation	Waitt Family Foundation	www.waittfoundation.org	The Waitt Family Foundation is dedicated to eliminating the gap between those who have Internet access and those who do not through the PowerUP program and other online resources.
International Organization	United Nations Information Technology Service (UNITeS)	www.unites.org	UNITeS has compiled an extensive list of examples of volunteers, citizens, and grassroots advocates using handheld computer or phone devices as part of their community service, volunteering, or advocacy. UNITeS has produced an *Online Software Directories for Handhelds.*
Legislators	U.S. House of Representatives		Various bills have been introduced in the House to promote access to and the diffussion of broadband services and Internet-access devices.
Nonprofit Consortium	MarcoPolo	www.marcopolo-education.org	MarcoPolo: Internet Content for the Classroom is a consortium of national education organizations, State education agencies, and the MarcoPolo Education Foundation that is dedicated to providing the highest quality Internet content and professional development to teachers and students throughout the United States.



U.S. Department of
Health and Human Services